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ABSTRACT

Following opening remarks by presiding committee member Matthew F. McHugh, this hearing record begins with a fact sheet inserted into the record which provides information on the following issues: infant mortality in the U.S. and in upstate New York; the inadequacy, unavailablity, or unaffordability of prenatal care; other obstacles to care including drug use; and the importance of parent education. Supplemental tables and graphs give data on the connection between infant mortality and low birthweight; federal maternal health programs; and medicaid coverage by state. The community Health Worker Program, a community-based family outreach program, and similar programs are described. Infant mortality, and child and maternal health problems, in Onondaga County and the city of Syracuse are discussed. A copy of the Onondaga County Infant Mortality Action Plan is included. Statistics cited highlight maternal and child health problems faced by black Americans. Nine health care professionals offered prepared statements and verbal testimony to the committee, and thirteen other interested individuals provided prepared statements. These statements and testimonies addressed the topics covered in the fact sheet, and other topics, including: poverty; adolescent pregnancy; syphilis; HIV infection; education; child abuse; health insurance; family planning; outreach programs; and problems of rural health delivery. (BC)

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# ENSURING HEALTHY BABIES IN UPSTATE NEW YORK: PRESSING PROBLEMS, PROMISING STRATEGIES

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## HEARING

BEFORE THE

## SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

HEARING HELD IN SYRACUSE, NY, JULY 16, 1990

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# ENSURING HEALTHY BABIES IN UPSTATE NEW YORK: PRESSING PROBLEMS, PROMISING STRATEGIES

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MONDAY, JULY 16, 1990

House of Representatives,
Select Committee on Children, Youth, and Families,
*Washington, DC.*

The select committee met, pursuant to notice, at 9:07 a.m., in the Main Conference Room, James M. Hanley Federal Building, Syracuse, NY, Hon. Matthew F. McHugh presiding.

Members present: Representatives McHugh and Walsh.

Staff present: Karabelle Pizzigati, staff director; Madlyn Morreale, research assistant; and Dennis G. Smith, minority staff director.

Mr. McHugh. Ladies and gentlemen, we want to welcome you here this morning and give a special word of appreciation to the witnesses who will be testifying and to our friends in the media who will carry your message out into the community.

Congressman Jim Walsh and his staff have been extraordinarily capable and hospitable to us, and we want to express our appreciation to them as well.

I have an opening statement. My name is Congressman Matt McHugh, and I serve with Congressman Walsh on the Select Committee on Children, Youth, and Families. And, of course, the hearing this morning is under the auspices of that committee.

We are dealing here with a very serious problem nationally, and a particular problem in Onondaga County and many communities in upstate New York, including some of mine in the 28th Congressional District. So, we are very grateful to all of you for being with us and sharing your observations and sharing your suggestions with us.

I will have a brief formal statement and then I will ask Jim to make any comments he would like. And then, as I think most of you know, we are going to do two panels of five each and we expect that each panel will have approximately one hour. We would ask each witness to try to limit your opening comments to five minutes, and we realize that may be a little bit tight, but we do want to leave some time for informal discussion, questions and answers which oftentimes is most helpful. We will have to break at about 11:15. Some of us have to catch a 12:10 plane back to Washington. But, again, we are very grateful for your being here and I will now make an opening statement for our record and then ask Jim for his.

Again, on behalf of the Select Committee on Children, Youth, and Families, I want to express the committee's very great concern for the problem of infant mortality. It is a crisis in our country. I want to express as well the committee's appreciation to our witnesses this morning for the insights that they will provide on the situation in New York State and on Onondaga County. Again, I would also like to thank Congressman Jim Walsh, and his staff for the work that they have done in highlighting the problem here and in making this hearing possible.

Since the select committee's inception in 1983, high priority has been given to the fiscal and developmental benefits of prenatal and primary health care. Congress has acted in a number of ways, including expanding Medicaid to reduce the financial barriers that keep too many low income women and children from receiving preventive health care services.

However, our nation still has a crisis. The United States ranks last among 22 developed nations in infant mortality—perhaps the most telling indicator of the health of a nation's children. Three hundred thousand infants die or are born with low birth weight every year.

The miracles of medicine have brought us a long way in saving dangerously small babies. However, medical technology has taken us about as far as we can go. What we have to do now is prevent low birth weight, the greatest determinant of infant death and disability, and then support families once their children are born.

After decades of steady improvement in the infant mortality rate, the 1980s ushered in a decade of stagnation. In 1987, the rate of low birth weight actually rose to its highest point since 1979.

Today, there is a new urgency. In growing numbers of U.S. cities, the infant mortality rate is increasing again. In fact, among U.S. cities, Syracuse has one of the highest infant mortality rates, higher than in New York City or Boston. In my own upstate district we face similar problems.

New and complex social crises have compounded the problem. Rising drug abuse, syphilis and HIV infection in pregnant women are putting even more newborns at risk. This is of special concern because the select committee has learned that pregnant substance abusers are much less likely to have access to prenatal care or appropriate drug treatment.

New York State health officials reported last year that if current drug abuse patterns continue, in 1995, five percent of all newborns in New York City alone could require costly neonatal intensive care. Upstate is clearly not immune, since crack addition is not limited to New York City, but is a growing problem in our communities.

These most recent and confounding problems come on top of much more pervasive failures in our health care and social service systems. Each year, more than one-third of pregnant women—more than one million women—receive prenatal care judged insufficient to guard against infant death or disability.

Financial barriers, including lack of health insurance, are by far the most common and significant reasons that women do not get adequate care. But there are other barriers as well, including unfriendly and demeaning services at times, inaccessible clinics with overworked staff, a critical shortage of private health care providers, bureaucratic confusion, and limited child care and transportation options.

This morning, we will hear from witnesses about the health care provider crisis in some rural areas of central New York that are paralyzing maternity care systems, the role that drug abuse and domestic violence may be playing to keeping women out of early prenatal care in Syracuse and Onondaga County, and the need for family planning and education.

Today we are fortunate to have the Director of the Division of Family Health in the New York State Health Department who will describe the success of state efforts to reduce financial barriers to care and to improve birth outcomes.

We will hear also from local officials regarding their efforts to reduce infant mortality, including a new community outreach worker program, enticements to private providers to encourage greater participation in providing care to high-risk populations, and the effects of a Fetal Alcohol Syndrome Demonstration Program.

We will hear about the first rural school-based clinic in New York State offering comprehensive services for teens, about critical parent education and home-based support services that assist families once their baby is born, and a mentoring program that matches pregnant teens with women from the community.

These efforts represent significant state and local strategies to confront the infant mortality crisis in New York. But there is still a long way to go. What is yet to be demonstrated at the national level is a concerted, systematic plan of action matched with resources to marshal all of the knowledge we have to combat this problem. Hopefully, this hearing will bring us one step closer to our goal.

Again, I welcome you all for being here. I look forward to your testimony.

At this point I would like to ask Congressman Jim Walsh for any remarks he would like to make.

[Opening statement of Congressman Matthew McHugh follows:]

## Opening Statement of Hon. Matthew McHugh, a Representative in Congress From the State of New York

On behalf of the Select Committee on Children, Youth, and Families, I would like to express the Committee's great concern about the infant mortality crisis, and to express the Committee's appreciation to our witnesses this morning for the insights they will provide on the situation in New York State and Onondaga County. I want to express particular thanks to my colleague, Congressman Jim Walsh, and his staff for facilitating our visit.

Since the Select Committee's inception in 1983, high priority has been given to the fiscal and developmental benefits of prenatal and primary health care. Congress has acted in a number of ways, including expanding Medicaid to reduce the financial barriers that keep too many low-income women and children from receiving preventive health care services.

However, our nation still has a crisis. The U.S. ranks last among 22 developed nations in infant mortality—perhaps the most telling indicator of the health of a nation's children. Three hundred thousand infants die or are born with low birthweight every year.

The miracles of medicine have brought us a long way in saving dangerously small babies. But medical technology has taken us about as far as we can go. What we must do now is prevent low birthweight, the greatest determinant of infant death and disability, and then support families once their children are born.

After decades of steady improvement in the infant mortality rate, the 1980s ushered in a decade of stagnation. In 1987, the rate of low birthweight actually rose to its highest point since 1979.

Today, there is a new urgency. In growing numbers of U.S. cities, the infant mortality rate is increasing. In fact, among U.S. cities, Syracuse has one of the highest infant mortality rates, higher than in New York City or Boston. In my own upstate district we face similar problems.

New and complex social crises have compounded the problem. Rising drug abuse, syphilis and HIV infection in pregnant women are putting even more newborns at risk. This is of special concern because the Select Committee has learned that pregnant substance abusers are much less likely to have access to prenatal care or appropriate drug treatment.

New York State health officials reported last year that if current drug abuse patterns continue, by 1995, five percent of all newborns in New York City alone could require costly neonatal intensive care. Upstate is clearly not immune, since crack addiction is not limited to New York City, but is a growing problem in our communities.

These most recent and confounding problems come on top of much more pervasive failures in our health care and social service systems. Each year, more than one-third of pregnant women—more than one million—receive prenatal care judged insufficient to guard against infant death or disability.

Financial barriers, including lack of health insurance, are by far the most common and significant reasons that women don't get adequate care. But there are other barriers, including unfriendly or demeaning services, inaccessible clinics with overworked staff, a critical shortage of private health care providers, bureaucratic confusion, and limited child care and transportation options.

This morning, we will hear from witnesses about the health care provider crisis in some rural areas of central New York that are paralyzing maternity care systems, the role that drug abuse and domestic violence may be playing in keeping women out of early prenatal care in Syracuse and Onondaga County, and the need for family planning and education.

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We will hear about the first rural school-based clinic in New York State offering comprehensive services for teens, about critical parent education and home-based support services that assist families once their baby is born, and a mentoring program that matches pregnant teens with women from the community.

These efforts represent significant state and local strategies to confront the infant mortality crisis in New York. But there is still a long way to go. What is yet to be demonstrated at the national level is a concerted, systemic plan of action matched with resources to marshal all of the knowledge we have to combat the problem. Hopefully, this hearing brings us one step closer to our goal.

Welcome, and I look forward to your testimony today.

# ENSURING HEALTHY BABIES IN UPSTATE NEW YORK: PRESSING PROBLEMS, PROMISING STRATEGIES

## *A FACT SHEET*

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## U.S. INFANT MORTALITY HIGHEST AMONG DEVELOPED NATIONS

- In 1987, nearly 39,000 babies died before their first birthdays. The U.S. ranks behind 21 developed countries in infant mortality, with an infant mortality rate (IMR) of 10.1 infant deaths per 1,000 live births. The African-American IMR (17.9) was twice the white rate (8.6). (Public Health Service, 1989; National Center for Health Statistics [NCHS], 1989)

- Two-thirds of all infant deaths occur in the neonatal period, or the first month of an infant's life. In 1987, the U.S. neonatal rate was 6.5 deaths per 1,000 live births, and the postneonatal mortality rate, deaths to infants age 1 month to 1 year, was 3.6 per 1,000 live births. (NCHS, 1989)

- Among 20 industrialized nations in 1986, the U.S. ranked 16th in postneonatal mortality and 19th in neonatal mortality. (NCHS, 1990)

## INFANT MORTALITY RATE IN UPSTATE NEW YORK CRITICALLY HIGH

- In 1988, over 3,000 babies died in New York State. While the State's IMR (10.7) declined slightly from 1985 (10.8), the African-American rate increased from 16.1 to 18.6 during the same years. (New York State Health Department [NYSHD], 1990; NCHS, 1987)

- Among U.S. cities in 1987, Syracuse's IMR (17.8) was among the highest, compared with the IMRs in New York City (12.7) and Boston (11.8). The Syracuse IMR increased from 16.2 in 1980 to 17.8 in 1987, then decreased to 12.7 in 1988. (National Commission to Prevent Infant Mortality [NCPIM], 1990; Onondaga County Health Department [OCHD], 1990)

- In 1988, infant mortality rates in other large Upstate cities ranged from 14.6 in Buffalo, to 14.0 in Albany, 12.0 in Rochester, and 9.5 in Binghamton. Seven Upstate counties ranked among the ten

New York counties with the highest infant mortality rates in 1988. These include Herkimer (15.2), Sullivan (14.2), Chemung (13.4), Seneca (13.4) and Orange counties (12.9). (NYSHD, 1990)

- In 1987, the African-American IMR in Syracuse (30.1) was three times higher than the U.S. rate (10.1). While African-American neonatal mortality remained relatively steady in Onondaga County between 1979 and 1987, the postneonatal mortality rate for African-Americans increased from 3.8 deaths per 1,000 live births to 14.6. (NCPIM, 1990; NCHS, 1990)

- In 1987, 24% of African-American postneonatal deaths in Onondaga County occurred when the mother was 17 years old or younger, while only 14% of live births were to mothers in this age group. (OCHD, 1990)

## LOW BIRTHWEIGHT/INADEQUATE PRENATAL CARE LINKED TO INFANT DEATH

- In 1987, the U.S. ranked 29th in the world in the percent of infants born too small. Nearly a quarter million infants (6.9% of all U.S. births) were born at low birthweight (LBW), or less than 2500 grams, the highest percentage since 1979. LBW infants account for 59% of all infant deaths and 73% of all deaths during the first month of life. (Children's Defense Fund, 1990; NCHS, 1985)

- Babies born to women who receive no prenatal care are more than three times more likely to be born LBW and almost five times more likely to die than those born to mothers who receive prenatal care in the first 3 months of pregnancy. (NCHS, 1985)

- In New York State, the low birthweight rate decreased from 7.7% in 1978 to 7% in 1984 and 1985, but rose to 7.8% in 1988. In 1988, nearly 10% of Syracuse infants were born at low birthweight, rising from 7.6% in 1980. African-American infants born LBW were 1.7 times more likely to die than white LBW babies in Onondaga County in 1988. (NYSHD, 1990; OCHD, 1990)

## MANY WOMEN RECEIVE INADEQUATE OR NO PRENATAL CARE

- One in 15 (6.1%) U.S. births in 1987 were to women who received late or no prenatal care. More than 74,000 pregnant women received no prenatal care, a 50% increase over the 1980 rate. Over one million women each year receive insufficient prenatal care. (NCHS, 1989; NCPIM, 1990)

- Infants born to teen mothers are 2-3 times more likely to be born LBW than infants born to mothers ages 25-29 and are twice as likely to die before age 1. In 1987, only 53% of pregnant teens received prenatal care in the first trimester of pregnancy compared with 79% of births to women ages 20-39. (NCHS, 1989)

- In 1987, New York State ranked 43rd in the U.S. in the percent of pregnant women who received early prenatal care (71%). Over 14,000 infants were born in New York to women who received no prenatal care. (Hughes, 1988; NCPIM, 1990)

## EARLY PRENATAL CARE UNAVAILABLE, UNAFFORDABLE FOR MANY

- One-fourth of women of reproductive age (15 million) have no insurance to cover maternity care; two-thirds of this group (9.5 million) have no insurance at all. (Institute of Medicine [IOM], 1988)

- One-third of women who lack health insurance begin prenatal care in the first trimester and make nine or more visits, compared with four-fifths of privately insured women. In 1987, 63% of surveyed Medicaid recipients and uninsured women, and 69% of low-income teens received insufficient prenatal care. (General Accounting Office [GAO], 1987)

- In 1987, 15 New York counties reported that more than 35% of women of child-bearing age were in families with incomes below 185% of poverty ($21,480 for a family of four). In 1988, 1.9 million nonelderly New York residents (12.5% of the population) lacked health insurance. (Alan Guttmacher Institute [AGI], 1987; Employee Benefits Research Institute, 1990)

- In New York, over 13,000 infants (5% of all New York births between 1984 and 1986) were born in counties that had no clinics that provided prenatal care. (AGI, 1989)

- More than one-third (37%) of obstetricians report they do not provide care to Medicaid patients. Obstetricians who do take

Medicaid recipients see, on average, about 12 patients each year. (Hughes, 1989)

## TRANSPORTATION, CHILD CARE, FEAR AND DRUG USE OBSTACLES TO CARE

- In two studies, 60% of Los Angeles County women and 73% of New York City women with no care stated that they had tried to obtain care but faced a variety of obstacles. (IOM, 1988)
- Attitudinal barriers were cited by 39% of surveyed women who obtained inadequate care: 22% cited fear of doctors and medical exams; 10% cited fear of arrest or deportation; 10% cited cultural biases against male providers. In a New York City hospital, 52% of women who had received no prenatal care cited fear of hospitals, doctors, or procedures as a primary reason for not seeking care. (GAO, 1987; IOM, 1988)
- Transportation problems were cited as a factor in preventing women from receiving adequate care by 38% of surveyed ob-gyns and 23% of interviewed women who received inadequate care. (American College of Obstetrics and Gynecologists [ACOG], 1989; GAO, 1987)
- Child care was cited as a factor in not obtaining sufficient prenatal care by 24% of surveyed ob-gyns and 16% of surveyed women. (ACOG, 1989; GAO, 1987)
- New York City cocaine abusers were seven times less likely than non-abusers to have received prenatal care. (New York City Department of Health, 1989)

## PRENATAL CARE, EARLY INTERVENTION, PARENT EDUCATION KEYS TO HEALTHY INFANTS AND COST SAVINGS

- In a recent study of 985 premature and low birthweight infants in eight U.S. cities, LBW infants who received early comprehensive medical and educational intervention from birth through age 3 had mean IQ scores 13.2 points higher than those in the control group. Children who did not receive the intervention services were almost three times more likely to have IQ scores indicating mental retardation. (The Infant Health and Development Program, 1990)

- In 1988, participants in the New York State Prenatal Care Assistance Programs had lower LBW rates than infants born to nonparticipating mothers with similar risk factors (7.6% compared with 10.1%). African-American participants were 65% less likely to give birth to LBW babies (9.5% compared with 14.3% of matched controls). (NYSHD, 1990)

- In Elmira, NY, participants in the Prenatal/Early Infancy Project, which provides comprehensive nurse home visits had improved diets, reduced cigarette smoking, reduced incidence of verified child abuse and neglect, lower numbers of emergency room visits, and increased use of informal support and community services. Most participants were employed longer and had fewer subsequent pregnancies. For mothers under age 17, birthweight improved by nearly 400 grams. (Olds, 1989)

- A survey of neonatal intensive care unit costs in 1985 show that if only 20% of LBW infants could be born at weights 250 grams heavier, $70-95 million could be saved. Every $1 spent on prenatal care saves $3.38 in the costs of caring for LBW infants. (Schwartz, 1989; Select Committee on Children, Youth, and Families, 1988)

7/16/90

Mr. McHUGH. Jim.

Mr. WALSH. Thank you very much, Matt. I would like to thank you for being here and welcome you to Syracuse. I would also like to thank Chairman Miller for calling this hearing. It is unfortunate the Chairman could not be here, but I want to assure everyone here today of his real sensitivity to this problem and his interest in today's testimony.

Congressman McHugh, as many of you know, is from Ithaca, New York, is a member of this committee, and is also a highly regarded senior Member of the Congress, and a highly respected force on the Appropriations Committee.

I prepared a formal statement and I have submitted it for the record. So instead of making my statement, I would like to give up my time to hear from the people I consider to be the experts. You.

For everyone's information, the people who will testify here today know a lot more about the problem than Congress does. They know a lot more about low birth weight, prenatal care and proper nutrition. That is why we are here today. We do not want to sit here wringing our hands. We want solutions. We want approaches.

I know our community has ideas. We are on the front lines of this war. We have a higher incidence of infant mortality than most other communities our size. I would like Congressman McHugh, and the committee staff who have traveled here from Washington today to hear how people in central New York work to care for one another.

I salute you, the people who are trying to solve this problem. I would like to welcome everyone, including the news people who are here today to help raise awareness of this horrible health dilemma that we face.

My formal statement includes some statistics I am sure others will mention. But when you hear these statistics, remember we are talking about infants, the most helpless among us.

Thank you.

[Opening statement of Congressman James Walsh follows:]

### OPENING STATEMENT OF HON. JAMES T. WALSH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

I want to thank Chairman Miller for convening this important hearing so that the Select Committee can gain a greater insight into one of the most vexing medical and social problems in our nation today. I want to also thank my colleague, Mr. McHugh, for chairing this hearing and for his support in making it a reality. This hearing is not only important to upstate New York, but to the nation as well. It is a continuation of the work the Select Committee began last October with a hearing on infant mortality in Washington, DC. I am pleased that one of today's witnesses, Dr. James Miller, was also part of that hearing. We look forward to learning about the progress Onondaga has made.

Nearly 40,000 babies born in the United States this year will not live to see their first birthday. While public attention generally focuses on infant mortality, the nucleus of this problem is the incidence of low birthweight. One-quarter of these infant deaths could be prevented with adequate prenatal care and proper nutrition. Although only 7 percent of all births are low birthweight, these babies account for almost 60 percent of all infant deaths.

The costs of caring for a single low birthweight infant can reach $400,000. In 1988, the hospital costs alone for low birthweight babies was approximately $2 billion. The cost of prenatal care which might prevent the low birthweight condition in the first place may be just $400.

National statistics do not give us enough information about infant mortality. We need to consider the differences among the states. In the past ten years, New York has reduced its infant mortality rate from 15.5 to 10.7, but still trails 26 other states, including New Jersey, West Virginia, Kentucky, and Texas.

Although the national infant mortality rate has declined to 9.9 percent, the United States ranks behind 21 other developed countries. This progress which has been made, however, disguises the fact that the infant mortality rate for blacks is twice the rate for whites.

There are three parts to the infant mortality issue—medical, social, and organizational. Much of the decline in the infant mortality rate over the past fifteen years has been attributable to technology. But we are reaching the technological limitations of acute care medicine for newborns. From the medical perspective, there is unanimous agreement that significant reductions in the infant mortality rate will depend on the increased use of preventive measures. Low birthweight is the major predictor of mortality in the first year of life.

From the social perspective, we must become aware of the relationship of drug use to infant mortality. Last fall, Dr. John Niles, the President-elect of the Medical Society of the District of Columbia, informed the Select Committee on Children, Youth, and Families that the infant mortality rate in D.C. had declined to 18 percent in 1983. But now the rate is nearly 30 percent. Dr. Niles blamed the increase solely on crack cocaine.

When examining the social variables which contribute to the infant mortality rate, we must also consider single parenthood and adolescent pregnancy. In many ways, infant mortality is as much a social problem as a medical one. Family life is a critical predictor of health status. Unmarried mothers are more than three times as likely as married mothers to obtain late or no prenatal care. The United States has an infant mortality rate which is twice that of Japan. To gain some insight into why this is so, compare the United States teenage pregnancy rate of 98 per 1,000 women to Japan which is 10 per 1,000. On the other hand, studies among migrants and refugees show that even the poorest of the poor can have healthy pregnancy outcomes if the supporting social structure is intact.

For our part, we policymakers should focus attention on the third part of the problem, the organizational aspect of the infant mortality rate. There is now ample evidence that patterns of miscommunication, poor coordination, and emphasis on function rather than mission plague our maternal health care delivery system. Last fall, the Assistant Secretary for Health told the Select Committee that there are 93 separate programs administered by 20 different agencies which have an impact on infant mortality. The current public maternal and child health care system offers services in a manner which virtually guarantees that a woman will face gaps in needed care.

In large measure, Congress is responsible for the lack of program effectiveness in maternal and child health programs. Fragmentation forces administrative officials to compete for resources and focus only on their program performance rather than to cooperate and work together on mutual goals. And it is a tragedy that Washington makes it so difficult for the local health professionals to use their expertise in providing care to some of our neediest citizens.

It is an honor to convene this hearing so that the Select Committee and all of our colleagues in Congress can become informed about the strategies you have undertaken to address this regional and national tragedy.

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# ENSURING HEALTHY BABIES IN UPSTATE NEW YORK:

# PRESSING PROBLEMS, PROMISING STRATEGIES

## Minority Fact Sheet

July 16, 1990

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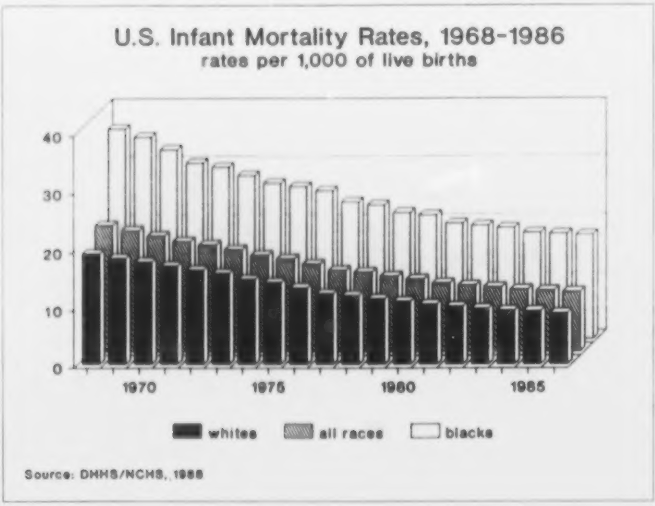
## FACTS AND FINDINGS

### U. S. INFANT MORTALITY RATES, 1968-1986



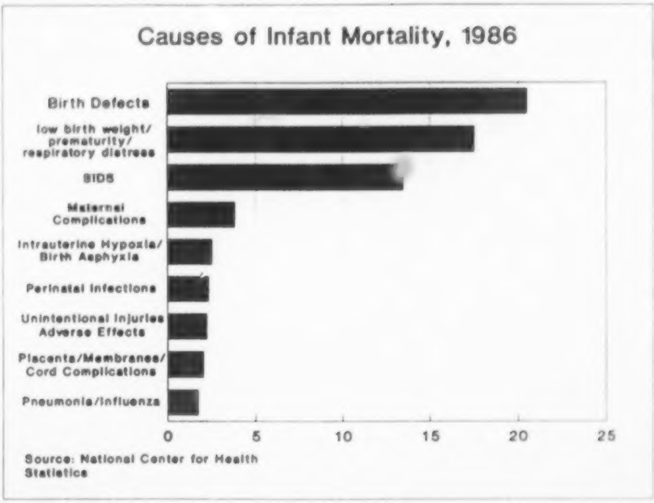
Source: DHHS/NCHS, 1988

o The decline of infant mortality rates in the 1970s, shown in the chart above, has been attributed largely to the invention of medical technology for the care of premature and other critically ill newborns. In the 1980s, this decline has slowed tremendously--partly because of a lack of progress in primary prevention of conditions which lead to infant death. [CDC, Morbidity and Mortality Weekly Report, Sept. 22, 1989, Vol. 38, No. 37, P. 635.]

- In 1978, the infant mortality rate for whites was 12.0 deaths per 1,000 live births; for blacks 19.2 per 1,000. One explanation for the higher rate of black infant deaths is that black births are more concentrated in the high risk groups. In 1983, 25.0 percent of all black births were to teenage mothers, compared to 12.0 percent of white births. According to the Department of Health and Human Services, black mothers are also more likely to receive late prenatal care. [The 1990 Health Objectives for the Nation: A Midcourse Review, Office of Disease Prevention and Health Promotion, Public Health Services, DHHS, 1986, pp. 36-39.]

- Factors known to have a negative impact on infant mortality include the continuing high rate of teenage pregnancy and barriers impeding access to prenatal, perinatal and infant care, particularly for high risk groups. [The 1990 Health Objectives for the Nation: A Midcourse Review, Office of Disease Prevention and Health Promotion, Public Health Service, DHHS, 1986, p. 37.]

CAUSES OF INFANT MORTALITY



o This chart shows the leading causes of infant mortality with birth defects, prematurity, and sudden infant death syndrome accounting for 52% of all infant deaths. Although infant mortality has declined during the 20th century, the percentage of infant deaths resulting from birth defects has increased steadily. In 1986 birth defects were an underlying or contributing cause of death for 9093 (23.3%) infants. The federal government and 22 states maintain surveillance systems for birth defects. (CDC, Morbidity and Mortality Weekly Report, Sep. 22, 1989, Vol. 38, No. 37, pp. 633-35.)

o Sudden Infant Death Syndrome (SIDS) is the most important cause of postneonatal mortality. In 1982, The rate for SIDS was 132.2 per 100,000 live births, accounting for more than a third of postneonatal deaths.

## LOW BIRTHWEIGHT

o The incidence of low birthweight (LBW) is an important indicator of infant morbidity and mortality. From 1975 through 1987, the overall incidence of low birthweight declined by 6.6%. Although LBW declined for both whites and blacks, the decline was substantially slower for black (2.9%) than for white (9.3%) infants. [U.S. Public Health Service, Centers for Disease Control, Morbidity and Mortality Weekly Report, 3/9/90, p. 149]

**LOW BIRTHWEIGHT - United States, 1975-1987**
(Rates per 1,000 live births; Less than 2,500 grams)

| Year | All Races | White | Black |
|---|---|---|---|
| 1975 | 73.9 | 62.6 | 130.9 |
| 1980 | 68.4 | 57.0 | 124.9 |
| 1985 | 67.5 | 56.4 | 124.2 |
| 1987 | 69.0 | 56.8 | 127.1 |

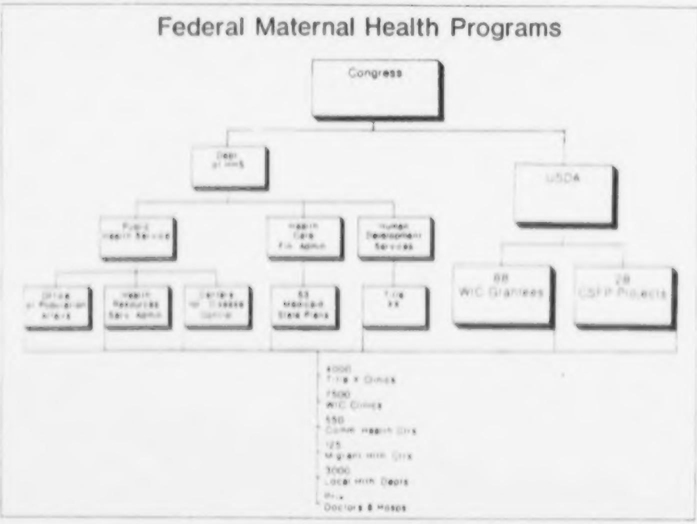
[Centers for Disease Control: **Morbidity and Mortality Weekly Report**, March 9, 1990/Vol. 39/No.9, p. 149. Public Health Service, US DHHS]

o "From 1981 through 1985, the rate for full-term LBW infants declined by 7%, but the rate for preterm LBW infants increased by 2%." [CDC, p. 149]

o "The decline in the overall rate of LBW is due to the reduction in the rate of full-term LBW infants. In comparing births by gestational period, we find greater improvement among black infants than white infants. Although preterm black infants have a higher incidence of LBW than white infants, black infants which are carried to term (greater than 37 weeks gestation) have a lower incidence of LBW. The greatest declines in low birthweight and very low birthweight (less than 1,500 grams) are for full-term black infants." [ibid.]

o "From 1981 through 1985, the rate for full-term LBW infants declined by 7%, but the rate for preterm LBW infants increased by 2%." [ibid.]

**MYRIAD PROGRAMS CHARACTERIZE FEDERAL GOVERNMENT ROLE**


Federal Maternal Health Programs
Congress
Dept of HHS
USDA
Public Health Service
Health Care Fin. Admin.
Human Development Services
Office of Population Affairs
Health Resources Serv. Admin.
Centers for Disease Control
53 Medicaid State Plans
Title XX
88 WIC Grantees
28 CSFP Projects
4000 Title X Clinics
7500 WIC Clinics
550 Comm. Health Ctrs
125 Migrant Hlth Ctrs
3000 Local Hlth Depts
Priv. Doctors & Hosps

o The U.S. Department of Health and Human Services (HHS) and the U.S. Department of Agriculture (USDA) share the responsibility for administering the maternal health programs. At HHS, authority is diffused through the Public Health Service, the Health Care Financing Administration, and the Office of Human Development Services. In turn, each of these divisions enter into grants and agreements with the states and private sector providers. USDA administers 88 grants under the Special Supplemental Food Program for Women, Infants and Children (WIC) and another 28 Commodity Supplemental Food Program Projects.

There is a second layer of administration at the grantee level, which is most often performed by a state. However, there may also be another separate grantee for a specific program within a state. Thus, authority may be further divided. Finally, maternal health services are actually delivered at the local level by a variety of providers including thousands of private doctors and hospitals, 4,000 Title X clinics, 7,500 WIC sites, 550 community health centers, 3,000 local health departments, and 125 migrant health centers.

This organizational chart does not include other types of programs which are only indirectly related to maternal health, but which are becoming increasingly important to healthy pregnancy outcomes. Such programs include alcohol and drug abuse prevention and control of infectious and sexually transmitted diseases, including the human immunodeficiency virus (HIV). Nor does this chart include the research component of lowering the infant mortality rate. Thus, if all programs were included, the chart would be significantly expanded.

o "A recently developed inventory of Federal programs related to infant mortality indicates a total of 93 Federal programs administered by 20 Federal agencies address issues related to infant mortality." [Statement of James O. Mason, M.D., Asst. Secy. for Health, HHS, for the Select Committee hearing "Caring for New Mothers: Pressing Problems, New Solutions," p. 35 of hearing record.]

## ATTITUDES AND BEHAVIORS INFLUENCE USE OF HEALTH AND SOCIAL SERVICES

o "Doubling the amount of money the nation currently spends on prenatal care, and making it universally available free of charge, will still not convince many pregnant women that taking advantage of such care is worth their time. " [Harmeet K. D. Singh, "Stork Reality - Why America's Infants Are Dying," Policy Review, Spring 1990, p. 62]

o "'I don't know how spending more on prenatal care is going to make any difference to the woman who uses crack. Use of drugs, not poor nutrition, is the leading cause of low birthweight. You hear a lot about how nutritional deficiencies, lack of funds for WIC, etc., are responsible for low birthweight, but that's simply false. (It) is not caused by poor feeding programs--it's usually caused by the behavior of the mother.'" [Dr. George Graham, prof. of human nutrition, Johns Hopkins Univ., in Singh, ibid., p. 63]

o "(M)ore and more health care experts...conclude that America's high rate of infant mortality, at least in certain areas, may be more of a social than a medical problem." [ibid., p. 63]

o "We must recognize that most of the world's major health problems and premature deaths are preventable through changes in human behavior and at low cost. We have the know-how and technology, but they have to be transformed into effective action at the community level." [World Health Organization Director General Dr. Hiroshi Nakajima in The State of the World's Children, 1990. UNICEF: Oxford Univ. Press, p. 14]

## FRAGMENTATION A BARRIER TO MCH SERVICES

o "We all have to recognize that our prenatal care system...is a patchwork, sort of crazy quilt of programs. Any effort to improve their coordination, to simplify their relationships, to build them together...is going to fix the problem, not incremental changes at the margin." [Sarah Brown, Prenatal Care Study Director, Institute of Medicine of the National Academy of Sciences, in Infants at Risk: Is the Federal Government Assuring Prenatal Care for Poor Women?, Testimony before the House Committee on Government Operations, 9/30/87]

o "Although a low-income woman may now be 'entitled' to prenatal care services under Medicaid, she often faces a cumbersome eligibility process, long waits for appointments, inhospitable conditions at health care sites, or no means of transportation to appointments." National Commission to Prevent Infant Mortality, Troubling Trends: The Health of America's Next Generation, Feb. 1990, pp. 6-7.]

o "Even when fully funded,...programs are difficult to coordinate because they are often independent of one another (with) separate administering agencies, rules, and guidelines..." [Institute of Medicine, Prenatal Care: Reaching Mothers, Reaching Infants, 1988, p. 70]

o "WIC services and prenatal care are not routinely coordinated...(L)ow rates of participation were attributed to many of the same barriers to coordination that exist between Medicaid and publicly financed prenatal services." [Ibid.]

o "We learned that things are really terrible out there in regards to maternity health service. And they are so terrible that the congressional penchant for incremental changes will not fix this problem. [Ezra Davidson. Select Committee on Children, Youth, and Families. Caring for New Mothers: Pressing Problems, New Solutions. Washington: 1990. p. 66.]

o "Expanding Medicaid alone, adding home visiting alone, supporting nurse midwives alone, increasing reimbursement alone, nothing alone will solve the problems. There must be major fundamental change in the ways we finance and deliver care for low-income women." [Davidson. p. 66.]

o "In this brief testimony, I would like to offer a radical proposition, namely, that Medicaid is part of the problem, and not part of the solution. We will soon be "celebrating" the 25th anniversary of Medicaid, yet during that period, the status of the U. S. infant mortality rate relative to those of other developed nations of the world has declined. The availability of providers willing to accept indigent pregnant women has declined, while the number and proportion of Americans uninsured for medical expenses, particularly those Americans in their prime reproductive years, has gone up. Teenage parenthood and single parenthood, two risk factors associated with risk of low birthweight and infant mortality, have also gone up. These are evidence of system-wide failure, yet we continue to consider piecemeal solutions which only tinker at the margins, solutions which have failed at every step to keep up with the pace of deteriorating circumstances among the weakest and most vulnerable of our population." [Jonathan B. Kotch, M.D., M.P.H., Chair, Council on Maternal and Child Health, National Association for Public Health Policy. Select Committee. p. 235.]

o "Categorical programs usually focus on well defined health problems which miss the broader health issues of an individual or family and in the strictest sense ignore the existences of other related services that could benefit the individual or family. Staff from one program cannot assist in another program, even though one may have down time due to "no shows" and another may be jammed. There is frequently duplication in record keeping and data reporting. All must be administered independently, which adds to the manager's workload." [Joan Eberly, R.N., M.P.H., Director of Personal Health Services, Berrien County Health Department, Benton Harbor, Michigan. Select Committee. p. 228.]

## MEDICAID COVERAGE FOR PREGNANT WOMEN AND YOUNG CHILDREN

o In 1986, Congress for the first time allowed states to "decouple" Medicaid eligibility from AFDC eligibility and enacted other changes to expand coverage for pregnant women and infants. All but two states have implemented the optional reforms in whole or part. In 1987, Congress authorized optional expanded coverage for women and infants (to age one) up to 185% of poverty level. As of April 1990, coverage for children (to age six) and pregnant women with incomes at or below 133% of poverty was made mandatory. This state-by-state table summarizes the scope of coverage for women and children:

**State Medicaid Coverage of Pregnant Women and Young Children, January 1990**

| *State* | *Coverage Above 133% of Poverty* | *Dropped Assets Test* | *Implemented Presumptive Eligibility* |
|---|---|---|---|
| Alabama | | ■ | ■ |
| Alaska | | ■ | |
| Arizona | | ■ | |
| Arkansas | | ■ | ■ |
| California | 185% | | |
| Colorado | | | ■ |
| Connecticut | 185% | ■ | |
| Delaware | | ■ | |
| Florida | 150% | ■ | ■ |
| Georgia | | ■ | |
| Hawaii | 185%* | ■ | ■ |
| Idaho | | ■ | ■ |
| Illinois | | | ■ |
| Indiana | | ■ | ■ |
| Iowa | 185% | | ■ |
| Kansas | 150% | ■ | |
| Kentucky | | ■ | |
| Louisiana | | ■ | ■ |
| Maine | 185% | ■ | ■ |
| Maryland | 185% | ■ | ■ |
| Massachusetts | 185% | ■ | ■ |
| Michigan | 185% | ■ | |
| Minnesota | 185% | ■ | |
| Mississippi | 185% | ■ | |
| Missouri | | | |
| Montana | | ■ | ■ |
| Nebraska | | ■ | ■ |
| Nevada | | ■ | |
| New Hampshire | | ■ | |
| New Jersey | | ■ | ■ |
| New Mexico | | ■ | ■ |
| New York | 185% | ■ | ■ |
| North Carolina | 150% | ■ | ■ |
| North Dakota | | | |
| Ohio | | ■ | |
| Oklahoma | | ■ | |
| Oregon | | ■ | |
| Pennsylvania | | ■ | ■ |
| Rhode Island | 185% | ■ | |
| South Carolina | 185% | ■ | |
| South Dakota | | ■ | |
| Tennessee | | ■ | ■ |
| Texas | | | ■ |
| Utah | | ■ | ■ |
| Vermont | 185% | ■ | |
| Virginia | | ■ | |
| Washington | 185% | ■ | |
| West Virginia | 150% | ■ | |
| Wisconsin | | | ■ |
| Wyoming | | ■ | |
| Total | 19 | 42 | 24 |

NOTE: * To be implemented at a future date.

SOURCE: National Governors' Association, 1990.

Mr. McHugh. Thank you very much, Jim.

I would like now to invite our first panel to come up and take their seats at the table. As they are coming up, and the first panel will include: Dr. Monica Meyer, who is the Director of the Division of Family Health with New York State Health Department in Albany; Dr. James Miller, who is the Commissioner of Health here in Onondaga County; Susan Stone, who is Prenatal Care Assistance Program Director with the Mary Imogene Bassett Hospital in Cooperstown; Mary Cooper, the Associate Administrator of Family Planning Services in Onondaga County Health Department; and Tom Herbek, Chief Executive Officer of the Family Health Network of Central New York and is Chairman of the Rural Migrant Committee Community Health Care Association of New York State in Cortland.

We are very grateful to all of you for being here. Let me mention for the record before we begin that we will include in the record a statement by the ranking Republican on the select committee, Mr. Bliley. And I would say to anyone here who does not have a statement for the record this morning that there will be a two-week period after the hearing during which you can submit for the record a statement which the committee would be delighted to receive.

[Statement of Congressman Thomas J. Bliley follows:]

### Statement of Hon. Thomas J. Bliley, Jr., a Representative in Congress From the State of Virginia and Ranking Republican Member

Frustration over our inability to lower the infant mortality rate has turned into puzzlement as we consider differences among the states. For example, Massachusetts now has the lowest overall infant mortality rate in the nation. But its rate among blacks is higher than the infant mortality rate for blacks in Louisiana, which has one of the nation's highest overall infant mortality rates. Connecticut, which has the highest per-capita income in the nation, has a higher black infant mortality rate than Arkansas, which ranks near the bottom of the income scale in 46th place.

What does this tell us about how services are organized and delivered to the population in need?

The current public maternal and child health care system is organized in a manner which virtually guarantees that a woman will face gaps in needed care. For example:

WIC enrollment among prenatal care patients averaged only 58 percent.[1]

[a] study in Hartford, Connecticut, showed that among teenagers under 18 there was a mean delay of almost 5 weeks between confirmation of pregnancy and a first prenatal visit.[2]

A study in Ohio found that, among a sample of low-income women, close to 40 percent waited 2 months or more after a positive pregnancy test to contact a prenatal care provider for appointment.[3]

The delivery of services to pregnant women and children has followed the scientific management model. Whether intentional or not, the federal government has tried to manufacture healthy children by using the same management model as it used to build bombers in World War II. That is, it broke the service system down into separate categorical programs among program specialists—social workers, dietitians, family planning counselors, prenatal care providers, etc. This strategy may be successfully employed in building an air force, but not for building strong families and healthy babies.

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[1] Institute of Medicine. *Prenatal Care, Reaching Mothers, Reaching Infants.* National Academy Press. Washington, D.C.: 1988.

[2] ———. p. 71.

[3] ———. p. 71.

The 101st Congress has continued this piecemeal approach to the problem of infant mortality. It has increased funding for the Maternal and Child Health Block Grant and the Special Supplemental Food Program for Women, Infants and Children (WIC), and has expanded Medicaid coverage for pregnant women and infants to those under 133 percent of the federal poverty level. In last year's Budget Reconciliation, authority was provided to fund small demonstration projects featuring "one-stop shopping," home visiting or case management out of the MCH Block Grant if funds are available. But there is no overall strategy to change the status quo.

For their part, states are taking advantage of these legislative changes to make improvements in the delivery system structure. As of January, 15 states now offer Medicaid coverage to pregnant women and children whose family income is up to 185 percent of the poverty level. Another 4 states offer coverage up to 150 percent of poverty. Forty-two states have dropped assets tests; half of the states have implemented presumptive eligibility;[4] 17 states have formed new authorities to coordinate programs and policies.[5] In 1980, Medicaid spending accounted for only 9 percent of all state spending. In 1990, it will account for nearly 14 percent. The states are doing exactly what the "experts" are advising them to do, but is it enough to overcome the problems built into the organizational structure?

We are rapidly approaching a point at which we must see results from these changes. Has Medicaid expansion really provided more services to more people, or has it merely shifted clients from other programs onto the Medicaid rolls? Has expansion resulted in the provision of medical services to those who were previously denied services, or has it simply shifted how the bill was paid? Has expansion to higher income groups reduced infant mortality rates among minority populations? Have Medicaid administrative reforms been successful in bringing those who were eligible for services but who did not participate into the service system? Has the increase in resources brought a proportionate reduction in the infant mortality rate? If these changes do not reduce the infant mortality rate, we must reconsider our entire approach to the organizational strategy on infant mortality.

There are a number of problems in the present fragmented delivery system. First, it creates competition for resources. Second, it is terribly wasteful. Each categorical program has generated its own set of bureaucratic demands to satisfy. While Washington is engaged in power politics, resources which could be used to serve clients are wasted on administrative costs. The Select Committee on Children, Youth, and Families visited a clinic in Connecticut last December which juggles 17 different Federal, State, and Local assistance programs. In a survey we conducted last fall on the availability of maternal and child health services, we found that 88 percent of providers receive support from more than one funding source. Seventy-seven percent receive funding from more than three sources. Multiple funding sources mean that there are multiple guidelines and reporting requirements as well as unpredictable fluctuations in funding amounts.

Third, it depends on the client to assemble the parts. This often creates new artificial barriers. For example, why is transportation a medical issue? Because Congress created a fragmented delivery system. The latest buzzword in health care, case-management, is neither a particularly new nor innovative idea. Case management is a reasonable response by local officials who are confronted by the problems presented by categorical programs, but we should also recognize it as another band-aid to fix a problem created by the fragmented system. Reimbursement for case management costs about half of prenatal care itself.

Fourth, when you set up a system to "produce" something, you have to produce something that can be counted. It is very difficult, if not impossible to prove cause and effect in a social services evaluation for the simple fact that so many variables must be considered. Thus, we tend to measure the process rather than what really matters, which is individual client outcomes.

Finally, the scientific management model assumes that there is someone overseeing the entire process and who is in charge of the final outcome. But it is clear that in the existing MCH health system, no one is really in charge of the major financial commitment to improve the lives and health of Americans. The services for pregnant women and children are really quite simple. But the administrative system has become so complex that no one is held accountable.

We need a results-oriented approach to the problem of infant mortality. The solution that I have offered, along with Congressman Walsh, the Consolidated Maternal and Child Health Services Act, is a creative approach to harness the combined power of more than $7 billion to improve the health care of mothers and children. This proposal recognizes that the incremental approach to health care management for pregnant women is a barrier, not a gateway, to further reduction in infant mortality and other poor health outcomes.

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[4] Jeffrey J. Koshel. *An Overview of State Policies Affecting Adolescent Pregnancy and Parenting.* National Governors' Association. (Washington, D.C.: 1990). p. 11.

[5] Koshel. p. 23.

This concept will eliminate barriers to comprehensive care by giving a woman immediate access to all services, from preventive services prior to pregnancy, to prenatal care including nutrition services during pregnancy, to postpartum care, all from a single provider. Delays in obtaining prenatal care will be eliminated. Children will receive immunizations, health care examinations, preventive laboratory testing, and nutritional services all in one place. Prevention will take its rightful place in the maternal and child health system to reduce infant mortality and long-term disabilities.

A consolidated delivery system offers great potential for breaking the welfare cycle, holding the line on skyrocketing health care costs, and for returning to the traditional federalist roles in which the Federal government provides the capital for states to manage as full-fledged partners. The Federal government should not make it so difficult for the state and local authorities to do their job in providing client-based care. The first step to making government programs "kinder and gentler" is to make them easier to use.

Mr. McHugh. I think, Dr. Meyer, we will start with you.

## STATEMENT OF MONICA MEYER, M.D., DIRECTOR, DIVISION OF FAMILY HEALTH, NEW YORK STATE HEALTH DEPARTMENT, ALBANY, NY

Dr. Meyer. It is the responsibility of the New York State Department of Health to protect and promote the public health of its citizens. A critical indicator of public health is infant mortality and its corollary low birth weight. In New York State, in 1989, infant mortality dropped for the first time in three years from a static 10.7 deaths per thousand births to 10.4 deaths per thousand, a three percent reduction in infant mortality. In upstate New York, this was a drop from 8.7 to 8.4 deaths per thousand. Similarly in New York State in 1989, low birth weight fell from 7.8 to 7.7 percent of all births, the first dip after a steady rise for the previous three years. The numbers are provisional, they are not dramatic, but they are significant.

While we are encouraged by this apparent trend, we are all too aware of its fragility in our society, a fragility that results from the many paradoxical factors contributing to the status of child health—increased entitlements to prenatal care and child health care and social support systems resulting from Medicaid expansions and various Title V and state programs on the one hand and on the other hand, deepening poverty—especially among children, increasing evidence of family and social disfunction as manifested by increasing rates of child abuse and neglect, growing documentation of prenatal substance abuse, non-declining rates of adolescent pregnancy and school dropouts despite investment of significant resources in adolescent pregnancy prevention and education. Let me briefly give some numerical evidence of these factors.

Poverty: In 1987, 23 percent of New York State children were living in poverty. And perhaps an even more sensitive indicator, during 1988, 25.5%, one quarter of the births listed Medicaid as the primary payor for delivery.

Adolescent pregnancy: There were over 1500 pregnancies to women 10 to 14 years of age in New York State, for a rate of 2.9 per thousand. Teenage New York State residents showed a 13 percent increase in pregnancy rate. Again, despite the resources being put into adolescent pregnancy prevention.

New York State's infant mortality rate, as I mentioned, in 1988 was 10.7 deaths per thousand live births. Nonwhite New York State residents had an infant mortality rate 58 percent greater than their white counterparts: 14.7 versus 9.3 deaths per thousand. The gap between white and nonwhite infant mortality has not changed substantially through 1988.

For New York State, excluding New York City, in 1987, the infant mortality rate for infants less than 2.5 kilograms, or less than normal birth weight, was 71.4 per thousand compared to 4.9 per thousand for babies weighing more than 2.5 kilograms. The low birth weight rate for nonwhite New York State residents was 12.7%, more than double the white rate of 5.9%.

To what do we attribute the fact that New York State still ranks significantly worse than the national rates of both infant mortality and low birth weight? Teasing out the multiple factors is difficult. We know that in upstate New York as a whole, we do better than the national average for both infant mortality and low birth weight, and yet there are significant geographic and ethnic pockets, as you both pointed out, in upstate New York where rates of infant mortality and low birth weight show great variance. For example, in Syracuse in 1987, infant mortality was 1.5 times the infant mortality rate in Onondaga County as a whole. And for this past decade, the nonwhite infant mortality rate was approximately 2.5 times the infant mortality rate among white infants in Onondaga County—27.4 deaths per thousand as opposed to 11.6.

Some indicators of morbidity that may be more specific to New York State and that are frequently interrelated are maternal HIV infection, syphilis, and substance abuse.

Between November 30, 1987 and December 31, 1989, New York State has tested anonymous blood samples from 581,605 newborn infants. Of these .65 percent were positive for HIV infection. The presence of HIV antibody in newborns indicates infection of the mother and not necessarily infection of the infant. But recent studies show that approximately 30 to 35 percent of infants born to HIV-infected mothers are themselves infected.

For those newborns with identified race or ethnicity on birth certificates, blacks and Hispanics accounted for 87 percent of the seropositives, but only 35 percent of the newborns tested. The statewide seropositivity rates by race or ethnicity were: 1.83 percent of all black newborns were positive for HIV infection, 1.3 percent for Hispanics, and .12 percent for whites. The prevalence of HIV infection among women giving birth over the past two years has remained constant. There has been no significant increase or decrease in HIV seropositivity among newborns during this period.

Syphilis: New York State has seen a doubling of the syphilis rate in children between birth and 19 years in the past two years. In addition, New York State has seen a dramatic increase in cases of congenital syphilis. Provisional 1989 reports indicate over a thousand cases of congenital syphilis in New York City, up from 357 cases in 1988, and 76 cases of congenital syphilis in 1989 for all of New York State, up from 20 cases, so that has more than tripled.

One of the significant contributors to fetal, infant, and child mortality and morbidity in 1990 is prenatal and maternal substance abuse. A national study suggests 11 percent of all newborns may be born to substance-abusing women. We do not have meaningful statistics at the present time on the extent of this problem in New York State, although vigorous efforts are developing to encourage pregnant women to voluntarily acknowledge substance abuse histories during prenatal care in order to increase counseling and referral to substance abuse programs. Clearly, this will only work for women receiving prenatal care.

A blinded random urine toxicology survey of pregnant and delivering women to determine extent and nature of substance abuse in the prenatal and perinatal period has been proposed. Although birth certificates and hospital discharge data are far from adequate indicators, there is a clear trend of increasing rates of neonatal drug discharges in New York State. In the state, excluding New York City, we averaged 3.3 drug-related discharges per 1000 births in 1988 up from a previous high of 1.8 drug-related discharges.

Education: Nearly one-third of all New York State students entering high school fail to graduate. Moreover, there are dramatic differences in the dropout rates between the regions and among various ethic groups. For the class of 1985, estimated dropout rates for Hispanic youngsters were 60 percent, for black 54 percent, for Native Americans 36 percent, and the estimate for white children was 21 percent.

Child abuse and neglect: There were 64,000 reported cases of child abuse and neglect in New York State in 1985, and 87,000 in 1988; an increase of 136 percent.

We are all familiar with the factors that contribute to improved birth and child health outcomes: access to prenatal care and child health care, access to care that is comprehensive, that has continuity, that enables establishment of a meaningful relationship between health care provider and patients, that is sensitive and responsive to individual and cultural values and belief systems, that is provided in a setting we can refer to as a medical home.

We are all aware that access to care has many components, especially when one is referring to high-risk families, those that have experienced personal as well as generational limited access to care; that it involves outreach initially and on a sustained basis. It involves education, again, both short term and long term. It involves an ecological approach to care, that is care sensitive to the priorities and needs of individuals within their environment.

Thus, the family that has been on welfare for three generations may not respond to a call for individual initiative-taking. A family with a child with intensive special care requirements may need respite before being able to provide stimulation to a toddler in the family. And a substance-abusing parent may need residential treatment, plus vocational training and job opportunities before being able to provide adequate parenting to her children.

It is with an awareness of these multiple factors together with innovative planning and commitment, curtailed at times by limited and regulated funding streams, that New York State has forged ahead. I would like to describe a few programs briefly.

Prenatal Care Assistance Program: PCAP began in 1984 as the Prenatal Care and Nutrition Program, and has grown from an initial annual enrollment of 11,000 in 1985 to over 33,000, the current year's expected total. At program inception, agencies willing to offer comprehensive prenatal services to medically indigent women were funded on a competitive basis. Starting January 1, 1990, primary prenatal care services under PCAP became an entitlement with the responsibility for reimbursement of services transferring to Medicaid.

Program functions such as outreach, public education, designation of providers, quality assurance and evaluation continue to be the responsibility of the Department of Health. The population targeted will include all pregnant women eligible for Medicaid—those at or below 185 percent of poverty. The number is estimated to be approximately 130,000 in New York State.

While we are most enthusiastic about the potential of this comprehensive entitlement program, we are cognizant of the many barriers to utilization imposed by certain Medicaid enrollment policies and regulations—some of these are federal, some state, and some local—as well as barriers resulting from some public perceptions of Medicaid. We urge you to work with us to overcome these barriers.

Comprehensive Prenatal-Perinatal Services Networks: This is a program establishing a local-level federation of health and human service providers and consumers who work jointly to identify and resolve problems of the regional service system. This year the networks' objectives are to increase prenatal and child enrollment in Medicaid and comprehensive health care with special outreach to substance-abusing populations.

The Community Health Worker Program is a community based, family focused outreach, case finding and case management program. A community health worker is a resident of the geographic area and a member of the specific population that is the focus of the program. The worker's background is similar in language, culture and socio-economic level to the majority of the families with whom she will work. The worker, therefore, understands the problems confronting the population and through her own life experiences has learned to overcome the obstacles or barriers to timely utilization of accessible and acceptable services.

Through home visits, the community health workers provide information, support, encouragement and assistance to families in the identification and resolution of problems that ultimately adversely affect the health status of the family.

There are Community Health Workers Programs currently in Onondaga County, in the Finger Lakes, the migrant project, and in the Oneida County Health Department.

The following case report is included to show the diversity of problems that the targeted population faces.

A 35-year-old woman was referred to the Community Health Worker Program. She was seven months pregnant with her third child, and had received no prenatal care. The community health worker found the client had very little food in her house, a non-functioning refrigerator and a stove that leaked gas. She smoked cigarettes and was taking a large amount of aspirin because of arthritis. She had few support systems and many anxieties. Community health worker intervention included: many contacts with the Department of Social Services to activate Medicaid and food stamps; making appointments for medical, prenatal care and WIC services and accompanying the client to her first appointment; help in obtaining food at food cupboards; discussing the effects of smoking, this woman did cut down on smoking and she was advised to discontinue aspirin until she consulted the doctor; making appointments which the client kept to obtain baby clothes at a community facility and showing the client places where she could obtain clothes free or at low cost; and helping the client obtain a functioning stove and refrigerator.

The community health worker also provided health teaching as well as emotional support and advocacy. Plans are to continue service until delivery and to assure health care for the new infant and other family members.

Infant Mortality Review: The Department of Health is providing project grants to six county health departments, including Onondaga County, to identify and examine the multiple factors which contribute to infant death through a new initiative, the Infant Mortality Review.

The IMR contains elements of the traditional case-by-case review of an infant death as a biomedical problem, but goes beyond analysis of these factors to identify the social, economic and systems factors unique to each community which have an impact on infant mortality and morbidity. The program empowers the community as the change agent and advocate for the health and well-being of its families. The comprehensive infant mortality reviews will enhance the community's ability to understand or "color in" those overall risk factors, such as, age, socio-economic status, and lack of prenatal care, that affect health outcome and thereby to develop a specific picture of health and human service needs for local families.

The IMR has the following objectives:

One, to initiate a community-based interdisciplinary review of infant deaths in each county with the goal of identifying specific local public health, human service and social interventions and policies that will address preventable factors related to these deaths;

Two, to conduct a public health nurse home interview with every mother who has experienced an infant loss in order to: obtain data not available in vital records or medical records, to assess ongoing family socio-economic and medical needs and jointly plan appropriate interventions with the family, and also to facilitate the grieving process.

Mr. McHugh. Dr. Meyer, let me interrupt you for a moment here.

Dr. Meyer. Yes.

Mr. McHugh. You have a very comprehensive statement which I have been reluctant to interrupt because it is so good and, obviously, it has an entire state perspective. But in fairness to the other people, I think I should ask you to close up.

Dr. Meyer. Okay.

Mr. McHugh. And then we can go back during the question period to cover those things that you think we did not cover adequately. But I do want to be sure the other people have a fair opportunity.

Dr. **Meyer**. Let me just name some of the other programs that we think are important.

Mr. **McHugh**. Yes.

Dr. **Meyer**. Certainly the WIC Program's caseload has grown 18 percent in the last two years. The school health program you are going to hear about in more detail that serves 75,000 children statewide. There is a new child health insurance program that has just passed both houses of the New York State Legislature and is awaiting the governor's signature that would create health insurance for all children up to age 13 who are at or below 185 percent of the federal poverty level and not eligible for Medicaid. This would require a premium of $25 to $100 to be paid by each family annually.

Another act that you should be aware of, our Neighborhood Based Initiatives Act, recently enacted by the New York State Legislature, is designed to meld and integrate currently disparate funding streams, to enable distressed neighborhoods to identify ways to expand and strengthen the services in their communities. A total of $2.5 million was appropriated to support this initiative.

In summary, much remains to be done to ensure the health of New York State's children, despite many significant efforts currently underway. We have no time to lose. The maternal and child health challenges we face are complex. What may sometimes be referred to as diseases of lifestyle, such as chemical dependency, pediatric AIDS and child abuse and neglect are resistant to traditional health care approaches and require innovation and multidisciplinary intervention.

The crises in maternal and child health care will tax all of our ingenuity, caring and patience and require an immense investment of resources. Jacob Riis, the turn-of-the-nineteenth-century social reformer, provided us with a useful analog: "When nothing seems to help, I would go and look at a stone cutter hammering away at his rock—perhaps a hundred times without so much as a crack showing in it. Yet at the 101st blow, it would split in two, and I know it was not that blow that did it, but all that had gone before."

The New York State Department of health has a hold on that hammer. Thank you.

[Prepared statement of Monica R. Meyer, M.D., follows:]

## PREPARED STATEMENT OF MONICA R. MEYER, M.D., DIRECTOR, DIVISION OF FAMILY HEALTH, NEW YORK STATE HEALTH DEPT., ALBANY, NY

### Ensuring Healthy Babies in Upstate New York: Pressing Problems, Promising Strategies

New York State Department of Health Testimony
Monica R. Meyer, M.D., Director, Division of Family Health
July 16, 1990

It is the responsibility of the New York State Department of Health to protect and promote the public health of its citizens. A critical indicator of public health is infant mortality and its corollary low birthweight. In New York State, in 1989, infant mortality dropped for the first time in three years from a static 10.7 deaths per 1000 births to 10.4 deaths per 1000, a 3% reduction in infant mortality. In upstate New York this was a drop from 8.7 to 8.4 deaths per 1000. Similarly, in New York State in 1989, low birthweight fell from 7.87% to 7.7% of all births, the first dip after a steady rise for the previous past three years. The numbers are provisional and not dramatic, but they are significant.

While we are encouraged by this apparent trend, we all all to aware of its fragility in our society, a fragility that results from the many paradoxical factors contributing to the status of child health -- increased entitlements to prenatal care and child health care and social support systems resulting from Medicaid expansions and various Title V and state programs on the one hand and on the other hand, deepening poverty -- especially among children, increasing evidence of family and social dysfunction as manifested by increasing rates of child abuse and neglect, growing documentation of prenatal substance abuse, non-declining rates of adolescent pregnancy and school drop-outs despite investment of significant resources in adolescent pregnancy prevention and education. I will briefly give some numerical evidence of these factors:

Poverty

In 1987, 23% of New York State children were living in poverty (1988 Current Population Survey, Department of Census). During 1988, 25.5% of the births listed Medicaid as the primary payer for delivery. New York City residents had 36.6% of their deliveries covered by Medicaid. Counties with 25% or more of resident births payed for by Medicaid include: Niagara, Erie and Chautauqua counties from Western New York; Allegany, Schuyler and Chemung counties from the Sourthern Tier; Cayuga, Oswego and Oneida counties from Central New York; St. Lawrence and Franklin counties from the Northcountry; Sullivan County from the lower Hudson Valley; Bronx, Kings and New York counties from New York City. It is important to do small-area analysis in addition to county-based statistics to determine the pockets of poverty within the larger geographic regions.

## Adolescent Pregnancy

There were 1532 pregnancies to women 10-14 years of age in New York State for a rate of 2.9/1000. Teenage (15-19 years) New York State residents showed a 13% increase in pregnancy rate from 76.7/1000 in 1980 to 86.6/1000 in 1988. Counties with teenage (15-19 years) pregnancy rates 70.0/1000 or greater include: Niagara and Erie counties from western New York; Monroe and Wayne counties from the Rochester area; Schuyler, Steuben and Chemung counties from the southern tier; Onondaga, Oneida and Chenango counties from central New York; Jefferson County from the Northcountry; Fulton, Montgomery, Schenectady, and Greene counties from the Albany area; and Suffolk county from Long Island.

## Infant Mortality

The New York State infant mortality rate in 1988 was 10.7 deaths per 1000 live births. Nonwhite New York State residents had a 1988 infant mortality rate 58% higher than their white counterparts, 14.7 versus 9.3 per 1000 respectively. The gap between white and nonwhite infant mortality had not changed substantially through 1988. Of the babies born in 1988, 3007 died before reaching their first birthday (10.7/1000). Of these, 2078 died during the neonatal period, a rate of 7.4/1000 live births. During the postneonatal period, 929 died, a rate of 3.3/1000 live births. The general reduction in infant mortality experience over the past 10 years is primarily due to a drop in the neonatal mortality rate. The post neonatal mortality decreased only 15.4 percent from 3.9/1000 in 1978 to 3.3/1000 in 1988.

## Low Birthweight

For New York State, excluding New York City, in 1987, the infant mortality rate for infants less than 2.5 kg. was 71.4/1000 compared to approximately 4.9/1000 for babies greater or equal to 2.5kg. The low birthweight rate for nonwhite New York State residents was 12.7%, more than double the white rate of 5.9%. The percentage of low birthweight births to women 19 years of age or younger was 10.4%. Counties with percent of births <2.5 kg., at 6.5% or greater include: Erie County from Western New York; Onondaga, Chemung and Herkimer countes from Central New York, Essex, Franklin and Warren counties from the Northcountry; Albany and Montgomery counties from the Albany area; Delaware and Sullivan counties from the Catskill area; Westchester country from the lower Hudson Valley; and Bronx, Kings, New York, Queens and Richmond counties from New York City.

To what do we attribute the fact that New York State ranks well below the national rates of both infant mortality and low birthweight? Teasing out the the multiple factors is difficult. We also know that upstate New York, as a whole, is above the national average for both infant mortality and low birthweight, yet there are significant geographic and ethnic pockets in upstate New York where rates of infant mortality and low birthweight show great variance. For example, in Syracuse in 1987, infant mortality rate (IMR) was 1.5 times the IMR in Onondaga County as a whole (18 deaths per 1000 live births vs. 12 deaths per 1000 live births) and non-white IMR was almost 2.5 times the IMR among white infants from 1980-1985 (27.4 vs. 11.6).

Some indicators of morbidity that may be more specific to New York state and that are frequently inter-related are HIV infection, syphilis, and maternal substance abuse.

## HIV Infection

Between November 30, 1987 and December 31, 1989, New York State has tested anonymous blood samples from 581,605 newborn infants. Of these 3786 (0.65%) were positive. The presence of HIV antibody in newborns indicates infection of the mother and not necessarily infection of the infant. Recent studies suggest that 30-35% of infants born to HIV-infected mothers are themselves infected. For those newborns with identified race or ethnicity, blacks and Hispanics accounted for 87% of the seropositives but only 35% of the newborns tested. The statewide seropositivity rates by race/ethnicity were: 1.83% for blacks, 1.30% for Hispanics and 0.12% for whites. The prevalence of HIV infection among women giving birth over the past two years has remained constant. There has been no significant increase or decrease in HIV seropositivity among newborns during the period, based on trend analysis of data by geographic area, age of the mother, or race/ethnicity of the infant (AIDS in New York State, NYSDOH, 1989).

## Syphilis

New York State has seen a doubling of the syphilis rate in children (0-19 years) from 1986 to 1988. In addition, New York state has seen a dramatic increase in cases of Congenital Syphilis. Provisional 1989 reports indicate 1017 cases of congenital syphilis in New York City, up from 357 cases in 1988 and 76 cases of congenital syphilis in 1989 for New York State, excluding NYC, up from 20 cases in 1988.

## Substance Abuse

One of the significant contributors to fetal, infant, and child mortality and morbidity in 1990 is prenatal and maternal substance abuse. A national study suggests 11% of all newborns may be born to substance abusing women. We do not have meaningful statistics on the extent of this problem in New York State although vigorous efforts are developing to encourage pregnant women to acknowledge substance abuse histories in order to increase counseling and referral to substance abuse programs. A blinded random urine toxicology survey of pregnant and delivering women to determine extent and nature of substance abuse in the prenatal and perinatal period has been proposed. Although birth certificates and hospital discharge data are far from adequate indicators, there is a clear trend of increasing rates of neonatal drug discharges in New York State. New York State, excluding New York City, increased from 1.8 drug-related discharges per 1000 births to 3.3 per 1000 births while New York City increased from 22.5 per 1000 births to 36.7 per 1000 births.

## Education

Nearly one-third of all New York state students entering high school fail to graduate (SED, Information Center on Education, 1986d). Moreover, there are dramatic differences in the dropout rates between the regions and among various ethnic groups. According to estimates produced by the New York Education Department, annual dropout rates in New York City are three times higher than those in the rest of the state (SED, Information Center on Education, 1982-83b). Associated with this disparity is a disproportionately high rate of school failure among minority students. For the class of 1985, estimated dropout rates for Hispanics (60%), blacks (54%), and Native Americans (36%) were at least two times those of whites (21%). (State of the Child, NYS Council on Children & Families, 1988.)

## Child Abuse and Neglect

There were 64,819 reported cases of child abuse and neglect in New York State in 1985 and 87,984 in 1988, an increase of 136%.

We are all familiar with the factors that contribute to improved birth and child health outcomes: access to prenatal care and child health care, access to care that is comprehensive, that has continuity, that enables establishment of a meaningful relationship between health care provider and patient, that is sensitive and responsive to individual and cultural values and belief systems, that is provided in a setting we can refer to as a "medical home." We are all aware that access to care has many components, especially when one is referring to high-risk families, those that have experienced personal as well as generational limited access to care. In involves outreach - initially and on a sustained basis. In involves education - again both short-term and long-term. It involves an ecological approach to care, that is care that is sensitive to the priorities and needs of individuals within their environment. Thus the family that has been on welfare for three generations may not respond to a call for individual initiative-taking; a family with a child with intensive special care requirements may need respite before being able to provide stimulation to a toddler in the family, and a

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substance-abusing parent may need residential treatment plus vocational training and job opportunities before being able to provide adequate parenting to her children.

It is with an awareness of these multiple factors together with innovative planning and commitment, curtailed at times by limited and regulated funding streams, that New York State has forged ahead. We have developed a variety of programs -- some of them community wide, some intensively focused on individuals, some during the prenatal period or earlier, some during childhood. I will review a few:

Prenatal Care Assistance Program (PCAP)

PCAP began in 1984 as the Prenatal Care and Nutrition Program, and has grown from an initial annual enrollment of 11,472 in 1985-86 to over 33,000, the current program year's (1989-90) expected total. At program inception, agencies willing to offer comprehensive prenatal services to medically indigent women were funded on a competitive basis. Grants were based on the need for services in a given area, the composition of the population in the provider's catchment area, and the willingness and ability of the provider to deliver a full range of services, including risk assessment, health education, care coordination, psychosocial assessment, primary care services, postpartum services, nutrition services, HIV counseling and testing services and quality assurance. With the passage of time and increasing success and growth of the program, the criteria for funding new projects expanded from areas of highest need to universal statewide coverage. Starting January 1, 1990, primary prenatal care services under PCAP became an entitlement with responsibility for reimbursement of primary prenatal services transferring to Medicaid. Program functions such as outreach, public education, designation of providers, quality assurance, development of new providers and evaluation continue to be the responsibility of the Department of Health, funded through state appropriation. The population targeted will include all pregnant women eligible for Medicaid (at or below 185% of poverty), estimated to be approximately 130,000. While we are enthusiastic about the potential of this comprehensive entitlement program we are cognizant of the many barriers to utilization imposed by certain Medicaid enrollment policies and regulations--some federal, some state, some local--as well as barriers resulting from some public perceptions of Medicaid. We urge you to work with us to overcome these barriers.

Comprehensive Prenatal-Perinatal Services Networks (CPPSN)

The CPPSN program underwent conceptual development in the period 1985-85. During 1985 and 1986, the five original networks, four located in the highest risk areas of New York City, and one in Buffalo, were developed through a combination of Department of Health encouragement and community-level organizational efforts. In 1986, the network project was expanded to include two rural sites selected on the basis of risk status and need for service improvement. These two sites were the lower Hudson Valley (Orange, Ulster and Sullivan counties) and the North Country (Jefferson, Lewis and St. Lawrence counties). Several additional networks are anticipated in 1990. The networks' mission is to reduce the incidence of infant mortality, morbidity and developmental disabilities, as well as the incidence of maternal mortality and morbidity. To this end, the networks' goal is to coordinate all services needed by infants and women of childbearing age to assure that appropriate services are available and accessible. This is accomplished through development of a functional local-level federation of health and human services providers and consumers who work jointly to identify and resolve problems of the regional service system. This year the Networks' objectives are to increase prenatal and child enrollment in Medicaid and comprehensive health care with special outreach to substance-abusing populations.

## Community Health Worker Program

The Community Health Worker (CHW) Program, a community based, family focused outreach, case finding and case management program, funded by the New York State Department of Health, is an example of a psychosocial support program developed to assist pregnant women and families gain access to the health, community and social services necessary for a healthy family.

The CHW is a resident of the geographic area and of the specific population that is the focus of the program. The worker's background is similar in language, culture and socio-economic levels to the majority of families with whom she will work. The worker, therefore, understands the problems confronting the population and through her own life experiences has learned to overcome the obstacles or barriers to timely utilization of accessible and acceptable services.

The CHW serves as an advocate for and a liaison between the family and the health, social support and community service system in the community. The scope of practice of the community health workers includes outreach, case finding, and case management, providing referrals to needed health and social and community services, follow-up and continuing support of individuals and families.

Through home visits, the CHWs provide information, support, encouragement and assistance to the families in identification, prioritization and resolution of problems that ultimately adversely effect the health status of the family even though the problems might not be defined as health or medically related.

An extensive education program has been developed to assist the CHWs perform their role with the families. By adding or modifying components of their education program, CHWs are prepared to work with different populations with special needs, populations such as school children and their families, migrants and seasonal farm workers, HIV positive pregnant women, or other groups for whom barriers exist in using the complex health and social service system.

In the fall of 1988, eight programs were implemented, three in New York City and five upstate using $1 million of Prenatal Care Assistance Program (PCAP) funds. In the fall of 1989, six new programs were implemented, two in New York City, two on Long Island and two upstate, at a total cost of $2,089,880.

Examples of Upstate New York CHW Program:

Onondaga County Health Department working closely with two community agencies, P.E.A.C.E., Inc. and the Southwest Community Center, and the City of Syracuse, in the spring of 1990, began a Community Health Worker Program. The program hired six CHWs and a program coordinator. Each of the community organizations houses three CHWs. The CHWs will focus their efforts in 17 census tracts: in the eastern census tracts section of the city known as Hilltop and in the south wedge. These are areas of the city that exhibit very poor pregnancy outcomes (infant mortality rates from 17.7 to 36.3 per 1000), substance abuse, poverty, and elevated frequencies of domestic violence and violent crimes. The objectives of this program are to improve pregnancy outcomes and parenting skills. The CHW training also was made available to the Onondaga County Department of Social Service Case Management program staff who were hired at the same time as the CHWs as well as other outreach staff employed by various programs within the Health Department.

The Finger Lakes Migrant Health Care Coordination Project is funded by the US Department of Health and Human Services, and is implemented by the Rushville Health Center in Rushville, New York. The project uses as a project design and training model, the CHW Program. The project, through the use of CHWs, has increased the access of the Migrant and Seasonal Farm Workers and their families to the needed health, social and community services. The project has enhanced the networking and the referral opportunities among the multi-county provider coalition. Through the provision of transportation, translation, advocacy, health education and risk assessment, the project has served to increase the availability and accessibility of services that are more culturally appropriate and timely.

The Oneida County Health Department implements a CHW program with four community health workers and one public health nurse coordinator to service both Oneida and Herkimer counties. Target areas served are: Cornhill section of Utica, the Sylvan Beach/Camden/Vienna area, Remsen/Poland and Cold Brook area, and the Bridgewater/West Winfield areas. The major barriers reported by the clients include: lack of transportation and lack of finances. The Office of the Aging transport vehicles have been used by program clients for prenatal transport to appointments. The major source of referrals to the program is the Public Health Nursing Services. This program is one of two upstate programs that serve a rural and/or a small urban area population.

Case Report:

The following case report is included to show the diversity of problems that the targeted population faces, the daily challenges that the CHWS resolve and the complexity of cases the CHWs coordinate. It should be pointed out that initially, for many clients, the CHW is the only health care worker that the clients will trust enough to let in their door and/or confide in.

- A 35-year old woman was referred to the CHW program. She was seven months pregnant with her third child, and had received no prenatal care. The CHW found the client had very little food in her house, a non-functioning refrigerator and a stove that leaked gas. She smoked cigarettes and was taking a large amount of aspirin because of "arthritis." She had few support systems and many anxieties. CHW intervention included:
    - many contacts with Department of Social Services to activate Medicaid, food stamps.
    - making appointments for medical, prenatal care and WIC services and accompanying client to first appointment. She is now being seen regularly in a high-risk clinic.
    - help in obtaining food at food cupboards.
    - discussing effects of smoking. She did cut down. Advising to discontinue aspirin until consulting a doctor.
    - making appointments which the client kept to obtain baby clothes at a community facility, and showing the client places where she could obtain clothes free or at low cost.
    - helping client obtain functioning stove and refrigerator through DSS.

The CHW also provided health teaching, as well as emotional support and advocacy. The plans are to continue service until delivery, and to assure health care for the new infant and other family members.

## Infant Mortality Review

The Department of Health is providing project grants to six county health departments, including Onondaga County, to identify and examine factors which contribute to infant death through a new initiative, the Infant Mortality Review (IMR).

The IMR contains elements of the traditional case-by-case review of an infant death as a biomedical problem, but goes beyond analysis of these factors to identify the social, economic and system factors --unique to each community-- which have an impact on infant morbidity and mortality. This program empowers the community as the change agent and advocate for the health and well-being of its families. The comprehensive infant mortality reviews will enhance the community's ability to understand or "color in" those overall risk factors (e.g., age, socioeconomic status, lack of prenatal care, etc.) that affect health outcome and thus to develop a specific picture of health and human services needs for local families.

The IMR process seeks to improve maternal and child health outcomes and reduce the incidence of infant mortality in New York State.

Toward this goal, the IMR has the following objectives:

- to initiate a community-based interdisciplinary review of infant deaths in each county with the goal of identifying specific local public health, human service and social interventions and policies that will address preventable factors related to these deaths;

- to conduct a public health nurse home interview with every mother who has experienced an infant loss in order to (a) obtain data not available in vital records or medical records, (b) assess ongoing family socioeconomic and medical needs and jointly plan appropriate interventions with the family and (c) facilitate the grieving process;

- to make recommendations regarding state policy to improve maternal and child health outcomes as an outgrowth of the community-based infant mortality review.

The three major elements of the program are:

1. data collection and community analysis of every infant death occurring in participating counties;

2. improved access to maternal - infant health and human services for families who have experienced a loss;

3. opportunity for community and statewide interventions to improve maternal and child health outcomes.

## WIC

WIC program caseload in the Syracuse region grew by 27.7% between 1988 and 1990 from 34,206 to 43,678. Onondaga County's caseload grew by 18.8% during this time period from 7,900 to 9,389.

The Bureau of Nutrition has been evaluating birth outcomes of babies born to women participating in the WIC program during pregnancy to birth outcomes of the general population in New York State. Preliminary data indicate that fewer low birthweight babies are born to women who had participated in the WIC program during pregnancy than to the general population.

## Primary & Preventive Health Care for Children, Birth to Five

The purpose of the Birth to Five program is to promote the health and well- being of children from birth to five years of age by reducing the preventable causes of childhood morbidity and mortality in high risk underserved areas of New York State. The program accomplishes this by enhancing existing primary and preventive health care services with activities designed to meet the special needs of the high risk populations served. Many of these enhanced services are designed to address the special needs of high risk infants and include such activities as: newborn parenting classes; outreach and home visits to new mothers; and promotion and support services for breastfeeding. Many of these enriched services may not readily be covered by anticipated expansions in Medicaid and other child health insurance programs in New York State.

Examples of Birth to Five Projects in Upstate New York:

Rushville Health Center:

The Rushville Health Center project supports a nurse practitioner who provides primary and preventive care services at the Rushville Health Center and two other clinic sites in rural Yates County, as well as an outreach worker who provides home visits and health education. Last year, direct care provided through this program included 682 well child visits, and 753 sick and/or follow-up visits. In addition, this program has an active educational component providing group presentations to day care centers, parent organizations, church groups, etc. They also write weekly child health newspaper columns in three local papers.

Tioga County Health Department:

The Tioga County project offers primary and preventive care to children in seven clinic sites in Tioga County. Last year the county provided 1,320 visits. In addition, this project has initiated a 24-hour access to care telephone service and parental group health education services.

## School Health Program

The School Health program, which began in 1983, provides comprehensive primary and preventive health care on-site at school-based clinics. The services provided include comprehensive physical exams, diagnosis and treatment of episodic illness, follow up and management of chronic illnesses, psychosocial counseling, immunizations, screenings, laboratory specimen collection, first aid and referral for specialty services when necessary. All School Health clinics require informed parental consent before enrolling students. Located at 112 school sites throughout the State with an enrollment of approximately 75,000 students, services are delivered at preschools, Head Starts, elementary, junior high and high schools. Localities include New York City, Buffalo, Rochester, localities in Westchester and Suffolk counties, and three rural districts in Cortland County.

## Child Health Insurance

Effective January 1, 1990, all infants to age 1 up to 185% of poverty became eligible for Medicaid. Effective October 1, 1990, all children to age 6 up to 133% of poverty will be eligible for Medicaid. In New York State, all other children are eligible for Medicaid up to approximately 86% of the federal poverty level.

A bill has passed both houses of the New York State legislature and is on the Governor's desk that would create a new health insurance program for children to age 13 who are at or below 185% of the federal poverty level and are not eligible for Medicaid. A premium of $25 to $100 would be paid per child per year. The State would subsidize all other costs. Services would include comprehensive primary and preventive ambulatory care. Families above 185% of poverty who are uninsured or underinsured would be able to buy into this plan. Still under negotiation is whether hospitalization costs would be included in the plan.

In addition to these child health insurance increases, New York State anticipates increased provider participation in Medicaid via a preferred provider option to become effective October 1st that will approximately triple current Medicaid payments for all primary and preventive child health care services to providers meeting certain standards, including EPSDT guidelines.

## Pre and Post Natal Parent Education Hospital Program (PPPEHP)

PPPEHP is a comprehensive statewide parent education program designed to reach every family during the crucial perinatal period. PPPEHP emphasizes the universal need for parenting services in the earliest months of the parent/infant relationship. Each year more than 200,000 New York State parents and their newborns are expected to benefit from the program. PPPEHP begins with Having a Baby: A Family Guide to Pregnancy. This attractive booklet provides expectant mothers with information about how to choose a health care provider, information about the first prenatal visit, and basic tips on how to stay healthy during pregnancy (such as eating the right foods, getting enough rest, and avoiding harmful substances). The booklet contains toll-free human services telephone numbers all pregnant women should know about, including the Healthy Baby Hotline, as well as information about other publications available from the Department of Health.

Postnatally, PPPEHP uses hospital-based professionals in an innovative team approach to parent education. The goal of the program is to ensure that every new mother is visited by a primary care nurse, pediatrician, social worker or psychologist, and nutritionist following childbirth in order to teach parents about basic baby care, offer advice on managing life with an infant, and help families connect with community parenting program and services. To assist professionals in working with new parents, the New York State Department of Health provides all 174 hospitals in New York State that offer maternity services with two free resources for parents: Welcome to Parenthood: A Family Guide and Welcome to Parenthood regional resource listings. Welcome to Parenthood: A Family Guide focuses on the social, psychological, and emotional needs of new parents, and provides some practical tips on parenting a newborn. Welcome to Parenthood: A Resource Listing is a regional directory that describes parenting programs and services available in each county. Professionals on the maternity units are being asked to distribute and review the information in the Welcome to Parenthood materials with all new parents prior to discharge. A parent hand-held child health record is being developed for inclusion with these materials. It is anticipated that child health care providers in New York State will participate in keeping this record up to date.

## Neighborhood Based Initiatives

The Neighborhood Based Initiatives Act was recently enacted by the New York State legislature. It is designed to meld and integrate currently disparate funding streams to enable "distressed neighborhoods" to identify ways to expand and strengthen the services in their communities, to improve the delivery of such services, and to help identify and eliminate barriers to the effective delivery of services to their residents. It is the intent of the legislature to first provide integrated and coordinated services for people in crisis or with a potential for being in crisis in selected distressed neighborhoods and then to assist neighborhoods in developing a long range overall plan to improve their overall economic and social condition via an assessment of the long term housing needs and economic needs of the community and a strategic plan for the stabilization and development of the community. A total of $2.5 million new dollars is appropriated to support this initiative.

In summary, much remains to be done to ensure the health of New York State's children, despite many significant endeavors currently underway.

We have no time to lose. The maternal and child health challenges we face are complex. What we may refer to as "diseases of lifestyle" such as chemical dependency, pediatric AIDS, and child abuse and neglect are resistant to traditional health care approaches and require innovation and multi-disciplinary intervention.

The crises in maternal and child health care will tax all of our ingenuity, caring and patience and will require an immense investment of resources. Jacob Riis, the turn-of-the-nineteenth-century social reformer, provided us with a useful analogy: "When nothing seems to help, I would go and look at a stone cutter hammering away at his rock--perhaps a hundred times without so much as a crack showing in it. Yet at the 101st blow, it would split in two, and I know it was not that blow that did it, but all that had gone before." The New York State Department of Health has a hold on that hammer.

Mr. McHugh. Thank you very much, Dr. Meyer. Again, your statement was very comprehensive and we appreciate it.

Dr. Miller, the Commissioner of Health here in Onondaga County, will go next.

## STATEMENT OF JAMES R. MILLER, M.D., M.P.H., COMMISSIONER OF HEALTH, ONONDAGA COUNTY HEALTH DEPARTMENT, SYRACUSE, NY

Dr. Miller. I want to thank you all for visiting Syracuse and Onondaga County to learn further about our situation and the efforts that we are making.

Let me increase the magnification of what Dr. Meyer has described to you, going from a statewide perspective to one particular upstate New York county, and I will also use Dr. Meyer's format of first describing what we know about infant mortality and then discussing our community's response, illustrating many of the programs that Dr. Meyer has already referenced.

I am going to rely on a number of graphic displays that our department has prepared. They are attached to the written statement that you each have, as well as appearing here on the easel.

The City of Syracuse ranks as having one of the highest infant mortality rates of 27 cities of comparable size using 1987 data. What you see here is cities across the nation, showing their infant death rate, the number of children who die among a thousand who are born. And Syracuse appears at the lower portion of this chart where we have infant mortality exceeding all of these other cities that are comparable to us in size.

And while that is itself notable, when we begin to look at who the children are, who the parents of the children are, we see other factors that we think deserve reporting. And then in the next graph you see infant mortality by maternal race. At the top of the chart, the state, the nation's and the City of Syracuse is white infant mortality being roughly equal. And the cities larger than Syracuse having a greater infant mortality rate when one looks at white children.

Looking at African-American infants, New York State and the nation has greater infant mortality, and the City of Syracuse has dramatically greater African-American infant mortality. So much so that when we look at the years 1984 through 1986, which we must do for statistical purposes, we do not have sufficient births in one year to African-Americans that we can reliably portray a single year, but among those larger cities, 1985 data show that Syracuse exceeds many American cities. And, in fact, exceeds all of the large cities as we show them here.

We noticed, my staff noticed that the committee has prepared a fact sheet, and we will supply you with additional information. But in the second section of your fact sheet, infant mortality rate in upstate New York is critically high. And in the second paragraph you do report that in 1988, our overall infant mortality did decrease, and you reference the national commission's report. But I would like to share with you some newly calculated data that again confirms locally that the 12.7 rate for Syracuse in 1988 is accurate, but our provisional 1989 rate is 14.5. And racially whereas in 1988, African-American infant mortality had dropped to 14.7, in 1989 it had returned to what was previously the level of 25.6. And through June 30th of this year the rate is running at 34.1. So we will provide additional copies. This was not submitted and we may not have even mentioned it in light of the other material that was provided.

We move on to our next attachment which is a map of the City of Syracuse showing the various census tracts. We know by analyzing data that, indeed, we have areas of the city that are particularly burdened with infant mortality problems and are burdened with higher rates of late or no entry to prenatal care, premature birth and children born below normal birth weight. These areas have sizeable African-American and low-income populations and relatively high rates of teen pregnancy.

Causes of neonatal mortality, that period being from birth through the end of the first month of life, are associated primarily with prematurity or congenital anomalies.

Post-neonatal mortality, from the period of one month through the end of the first year, is largely from Sudden Infant Death Syndrome.

Again, returning to a racial comparison, black neonatal mortality is two times that of whites and black post-neonatal mortality is three to four times that of whites.

Low birth weight, prematurity, and late and no entry into prenatal care are primary influences on infant mortality. Black race, poverty, and teen motherhood are also associated factors.

The next attachment, Attachment D, shows the percentage of births to women age 17 and under. Again it is a slightly different figure than Dr. Meyer, in which all teenage pregnancies were reported. We are looking at women 17 and under. And in the City of Syracuse, one of every six births occur to a woman who was less than 18 among African-Americans as compared with 2.6 percent of all births to whites in the city of Syracuse in that same age group.

Attachment E shows the percent of black births with late or no prenatal care, and it shows the sharp rise from 1981, on the left of the chart, from around 2 percent up to the 5 percent that was observed in 1986 and 1987. And our analysis of 1988 data shows that this number has grown recently.

Attachment F shows the mortality for low birth weight black infants being 1.7 times that for low birth weight white infants, recognizing that low birth weight is a major risk factor to early death. When one simply looks at all children born with a low birth weight, there is a racial discrepancy. Black infants as compared with white infants of low birth weight die at a greater rate. But for normal weight infants, black infant mortality is approximately four times that of whites.

That is what we know about the problem. We are continuing to try to further understand it.

The County Executive's Office has demonstrated great commitment and direction to the Departments of Social Services, Mental Health and Health, a commitment made difficult by the limited state and federal revenues, including significant loss in revenue sharing.

Our county government has worked closely with local health providers, and various community organizations, and has developed and begun implementing an action plan to provide greater access to health care and support services for pregnant women and their newborn children. This action plan includes: case management coordination, medical care, social support services and evaluations systems. They are briefly listed in Attachments G and H.

The various components, and there are a number of them, can be summarized into particular areas. One is the extending outreach into communities of high risk. We have taken advantage of many federal and state funding opportunities throughout county government to enable women from neighborhoods that are experiencing greater rates of infant mortality to serve their neighbors, and we have used the New York State Community Health Worker Grant, Comprehensive Medicaid Case Management, and the prenatal care program monies to augment our public health nursing teams as well as the PCAP, Prenatal Care Assistance Program Outreach and Education.

The coordination of comprehensive prenatal care has enabled us to bring to the clinic settings where ambulatory care is provided, the number of social services, including both Medicaid and WIC.

We are attempting now in various ways to eliminate barriers caused by lack of transportation and child care. We are committed to assessing the roles that drug and alcohol use, child abuse and neglect and domestic violence are contributing to infant mortality, and we have been now looking specifically at Fetal Alcohol Syndrome and fetal alcohol affects, documenting the extent of this problem in our community and addressing the available services to help prevent and care for children who suffer from fetal alcohol exposure.

And finally, we are developing a computerized data base to track women and their newborn children as well as to assess, evaluate and monitor the impact of the programs in place.

Nevertheless, a number of other factors are in dire need of intervention. These include the shortage in our community of prenatal care providers for low-income families, although it is encouraging that a growing number of physicians have joined our program and we are very encouraged by that willingness on physicians part. We also need to access and assure that there is access to culturally sensitive and dignified care and improve the socio-economic context in which infants are born.

"Infant mortality is a social problem with health consequences." I am quoting Masden Wagner. Employment opportunities, job training, education, safe and affordable housing, and standard of living all need to be addressed. A comprehensive community-wide strategy to impact each of these is essential to assure that the cycle of poverty which perpetuates our very high infant mortality rate can be reduced.

[Prepared statement of James R. Miller, M.D., follows:]

## Prepared Statement of James Miller, M.D., MPH, Commissioner of Health, Onondaga County Health Department, Syracuse, NY

U.S House of Representatives Select Committee on Children, Youth, and Families Field Hearing on July 16, 1990.

Thank you for visiting Syracuse and Onondaga County to explore barriers to care as we perceive them in Upstate New York and to review our proposed action plan

The local infant mortality crisis as reported by the Onondaga County Health Department Bureau of Surveillance and Statistics is portrayed in the following graphic presentations.

**Attachment A** The City of Syracuse is ranked as having the highest infant mortality rate of 27 cities of comparable size based on 1987 data.

**Attachment B** The rate for black infants is higher than in 18 large urban centers based on 1985 data.

**Attachment C** The areas with the highest infant mortality rates are the West, South and East Fayette neighborhoods within Syracuse. These areas generally coincide with areas having late or no entry into prenatal care, prematurity and low birthweight. These areas have sizeable black and poor populations with relatively high rates of teen pregnancy.

- Causes of neonatal (birth to one month) mortality are associated primarily with prematurity or congenital anomalies.

- Postneonatal (one month to one year) mortality's largest cause is Sudden Infant Death Syndrome (SIDS).

- Black neonatal mortality is 2 times that of whites and black postneonatal mortality is 3 to 4 times that of whites.

- Low birth weight, prematurity, and late/no entry into prenatal care are primary influences on infant mortality. Black race, poverty, and teen motherhood are also associated factors.

**Attachment D** The percentage of births to women age 17 and under for City of Syracuse Blacks is 16.1% as compared to 2.6% for City Whites in the same age group.

Testimony of James R. Miller, MD (Continued)

**Attachment E** The percentage of Black births with late or no prenatal care have risen sharply between 1981 and 1987, from 2.0% (1981-1982 avg.) to 5.0% (1986-1987 avg.).

**Attachment F** Mortality for low birth weight Black infants is 1.7 times that for low birth weight White infants. For normal weight infants, Black mortality is approximately 4 times that of Whites.

Onondaga County Government, working closely with local health providers and various community organizations have developed and begun implementing an action plan to provide greater access to health care and support services for pregnant women and infants. This extensive action plan includes case management coordination, medical care, social support services and evaluation systems. (Attachments G and H)

Specifically this plan addresses access to prenatal care issues by:

1. extending outreach to high risk families (e.g., New York State Community Health Worker Grant, Comprehensive Medicaid Case Management, Augmentation of Public Health Nursing Teams, PCAP Outreach and Education)

2. coordinating comprehensive prenatal care with social services on-site including Medicaid and WIC enrollment.

3. exploring options to eliminate barriers to care created by lack of transportation and child care

4. assessing the role of drug and alcohol use, child abuse and neglect, and domestic violence as contributors to infant mortality (e.g., Fetal Alcohol Syndrome Grant)

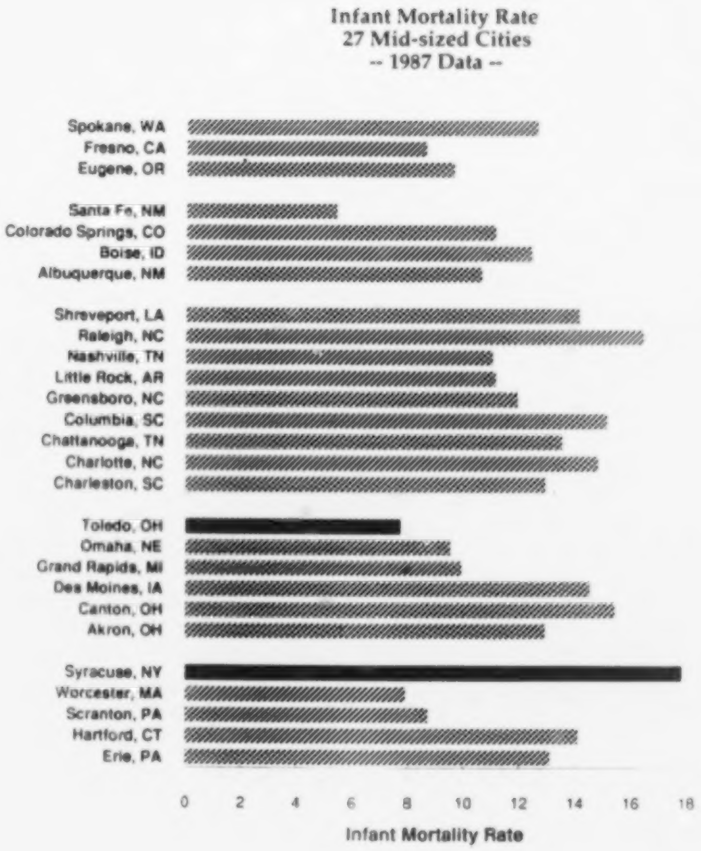
5. developing a computerized database to track women and infants as well as to assess, evaluate and monitor the impact of programs in place.

Nevertheless, a number of other factors are in dire need of intervention. These include the shortage in our community of prenatal care providers for low income groups, access to culturally sensitive and dignified care, and improvements in the socioeconomic context in which infant mortality occurs.

"Infant mortality is a social problem with health consequences."[1] Employment opportunities, job training, education, safe and affordable housing, and standard of living need to be addressed. Without a comprehensive community wide strategy to impact each of these, individuals will remain in the cycle of poverty which perpetuates our very high infant mortality rate.

[1] Wagner, Masden. "Infant Mortality In Europe: Implication for United States." Journal of Public Health Policy, Winter 1988, pp.473-484.

ATTACHMENT "A"

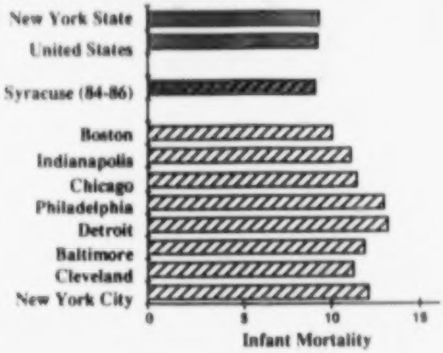


Infant Mortality Rate
27 Mid-sized Cities
-- 1987 Data --

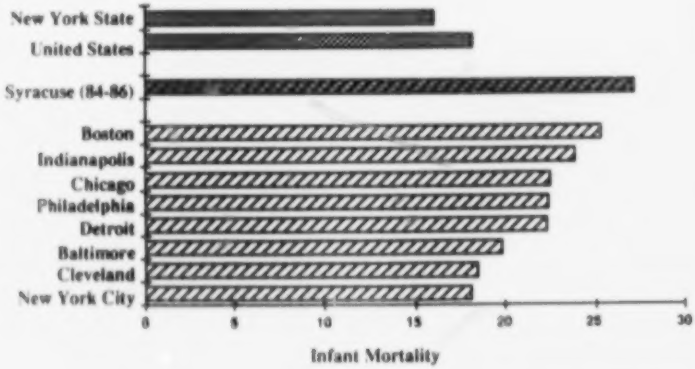
ATTACHMENT "B"

# SYRACUSE RELATIVE TO OTHER CITIES, 1985. INFANT MORTALITY RATE BY RACE

**WHITE INFANT MORTALITY**



**BLACK INFANT MORTALITY**

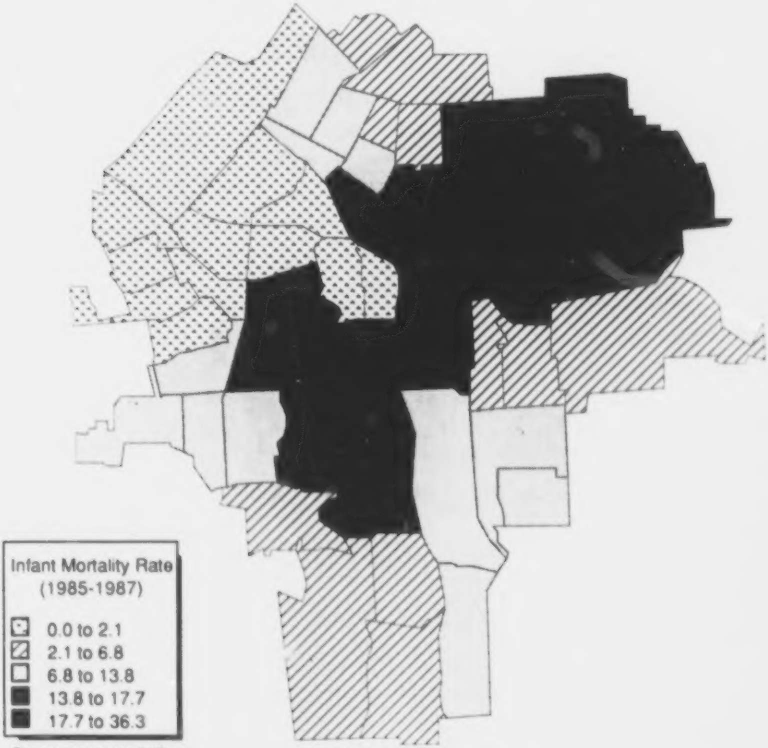


Data sources: NYS Vital Records and Children's Defense Fund
Analysis and Graph by: Bureau of Surveillance & Statistics, Onondaga County Health Department.

ATTACHMENT "C"

# Infant Mortality Rate

City of Syracuse 'Neighborhoods'

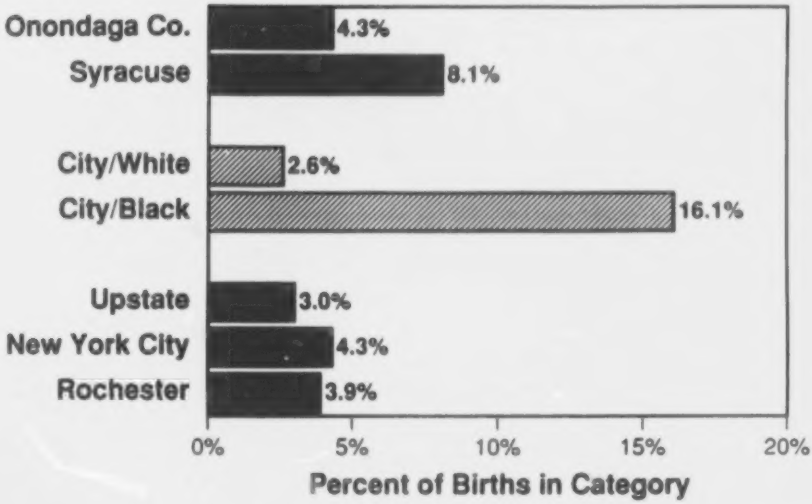

Infant Mortality Rate
(1985-1987)
▨ 0.0 to 2.1
▨ 2.1 to 6.8
☐ 6.8 to 13.8
■ 13.8 to 17.7
■ 17.7 to 36.3

Data ranges are quintiles

Note: "Neighborhoods" are defined as contiguous groups of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census.
Data Source: New York State Bureau of Vital Statistics
Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics

ATTACHMENT "D"

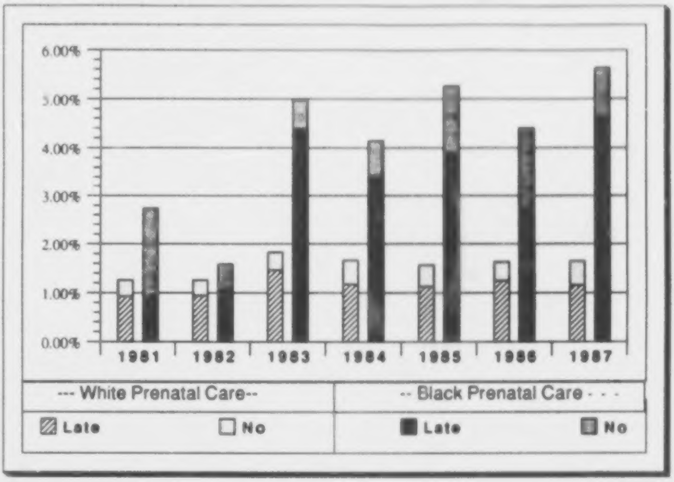
## Percent of Births to Women Age 17 and Under



Data are 1985-1987 Averages
Data source: NYS Vital Statistics
Analysis and Graph by: Onondaga County Health Department
Bureau of Surveillance & Statistics

ATTACHMENT "E"

## Entry to Prenatal Care by Race and Year
## Onondaga County, NY 1981-1987



**Note:**

Late care= Entry in third trimester of pregnancy
No Care = No prenatal care before delivery.

Data Source: New York State Vital Records
Analysis and Graph prepared by Onondaga County Health Department
Bureau of Surveillance and Statistics

ATTACHMENT "F"

## BirthWeight- and Race- Specific Infant Mortality
## Onondaga County, 1985-1987

| BIRTHWEIGHT CATEGORY | White | Black | Total | B/W Risk Ratio |
|---|---|---|---|---|
| **Normal (≥ 2500 g)** | | | | |
| **Births** | 17,058 | 2,312 | 19,370 | |
| **% of Births** | 94.6% | 86.7% | 93.5% | |
| **Deaths** | 50 | 26 | 76 | |
| **IMR** | **2.9** | **11.2** | **3.9** | **3.84** |
| **Low (< 2500 g)** | | | | |
| **Births** | 981 | 355 | 1,336 | |
| **% of Births** | 5.4% | 13.3% | 6.5% | 2.45 |
| **Deaths** | 83 | 53 | 136 | |
| **IMR** | **84.6** | **149.3** | **101.8** | **1.76** |

Data Source: NYS Vital Records
Analysis by: Bureau of Surveillance & Statistics
Onondaga County Health Department

ATTACHMENT "G"

# INFANT MORTALITY ACTION PLAN

## A. OUTREACH & CARE COORDINATION

1. PCAP TRANSITION
2. TEENAGE SERVICES ACT (TASA) EXPANSION
3. COMPREHENSIVE MEDICAID CASE MANAGEMENT (CMCM)
4. NEW YORK STATE COMMUNITY HEALTH WORKER GRANT
5. AUGMENTATION OF PUBLIC HEALTH NURSING TEAMS
6. CASE MANAGEMENT PROVIDER GROUP
7. ACCESS CENTER

## B. MEDICAL

1. PCAP TRANSITION
2. OPENING OF FAMILY HEALTH SERVICE CLINIC
3. DRUG AND ALCOHOL SERVICES
4. FETAL ALCOHOL SYNDROME GRANT

## C. FAMILY AND SOCIAL SUPPORTS

1. OUTSTATIONING FOR MEDICAID INTAKE
2. OUTSTATIONING FOR WIC INTAKE
3. TRANSPORTATION
4. CHILD CARE FOR CLINICAL PURPOSES
5. DRUG & ALCOHOL SERVICES
6. DOMESTIC VIOLENCE
7. CHILD ABUSE AND NEGLECT

## D. ASSESSMENT & EVALUATION

1. SURVEILLANCE ACTIVITIES
    a. INFANT MORTALITY REVIEW
    b. DRUG AND ALCOHOL SURVEILLANCE
    c. ANALYSIS OF VITAL RECORDS INFORMATION
2. ACCESS CENTER

ATTACHMENT "H"

# Onondaga County Infant Mortality Action Plan

May 14, 1990

## I. INTRODUCTION - THE PROBLEM

Infant Mortality is an important variable for understanding the health of populations. The infant mortality rate, usually expressed as the number of infant deaths per 1000 live births, is a key indicator of community health because it measures the health of the most dependent and most vulnerable segment of any population. The infant mortality rate of a population serves as an important epidemiological indicator of other critical issues, such as the adequacy of prenatal care, the nutritional status of the mother and child, access to medical care, and a host of socio-economic variables. For these reasons, infant mortality is often used as the principal variable when comparing the health of populations in varying areas and facing varying socio-economic conditions.

The infant mortality rate in Syracuse is higher than that in 27 cities of comparable size. The black infant mortality rate is disturbingly high (27.4 deaths per 1000 live births during 1981 - 1987). Compared with 18 large cities including New York, Boston, Chicago and Detroit, Syracuse has the highest black infant mortality rate of all. Because the mortality rate for white infants in this county is relatively low (9.2/1000 for the same period), the risk to black infants is nearly triple that of whites. Thus the black:white risk ratio for Onondaga County is also the highest of any in the aforementioned group of cities. Beginning in 1983, much of the elevated risk to blacks has been concentrated in the postneonatal period, i.e. from 28 days to one year of age.

Infant mortality in the City of Syracuse is considerably higher than the remainder of the County. Average rates for 1981 through 1987 are 15.4 for the City, and 8.8 for the remainder of the County. The average risk ratio for City/County is 1.75 (range = 1.4 to 2.3), meaning that a child born in the City of Syracuse is 75% more likely to die during its first year than a child born outside of the City. (See Data Summary in Attachment A)

### LEADING RISK FACTORS

A. Late/No Prenatal Care
    Identified Barriers To Care:
        a. Financial
        b. Poor Coordination of Services
        c. Lack of Transportation
        d. Lack of Child Care
        e. Substance Abuse
B. Low Birth Weight/Prematurity
C. Teen Pregnancy
D. Minority Status
E. Poverty
F. Domestic Violence
G. Substance Abuse
H. Parenting Issues
I. Inadequate Pediatric Health Care
J. HIV

## II. COMMUNITY ACTIVITIES

A. County Executive Office established the Access to Care Committee
B. Trip to Toledo, Ohio to observe and review Infant Mortality Prevention Efforts
C. Trip to Hartford, CT to observe and review Infant Mortality Prevention Efforts
D. Human Service Forum - January, 1990
E. Neighborhood Based Initiatives
F. Fowler Project
G. Case Management Provider Group
H. Access Center Development with Syracuse University
I. Networking with Medical Society
J. Presentations to Numerous Community Groups

## III. ACTION PLAN

The Onondaga County Departments of Health and Social Services are engaged in a number of joint initiatives designed to improve maternal and infant health outcomes and reduce infant mortality. The Departments are working closely with local health providers and community organizations to provide greater access to health care and support services for pregnant women and infants. This extensive action plan includes the coordination of case management, medical care, social support and evaluation services.

### A. OUTREACH & CARE COORDINATION

1. PCAP Transition
Effective January 1, 1990, Medicaid assumed the role of fiscal administrator of New York State's Prenatal Care Assistance Program (PCAP). This expands Medicaid eligibility to include pregnant women and infants up to one year of age whose family does not exceed 185% of the federal poverty level. During the first three months of 1990 there were 388 new cases opened for Medicaid using these new standards. As these new eligibility requirements become known throughout the community, it is assumed the caseload will continue to rise at an increased rate. Therefore, it is estimated that 1,200 to 1,500 additional Medicaid cases will be opened this year under the PCAP program.

2. Teenage Services Act (TASA)
   TASA is contracted through DSS to The Salvation Army and offers supportive counseling and case management to pregnant and parenting teenagers. Presently, the TASA program covers teenagers through their eighteenth birthday who are in receipt of ADC Public Assistance benefits. In 1990, TASA will expand to include teens through their 19th birthday in all categories of assistance. This is estimated to increase the number served from 150 teens in 1989 to 500 in 1990.

3. Comprehensive Medicaid Case Management (CMCM)
   In addition to TASA, the Department of Social Services currently funds the CMCM Pilot. The purpose of the CMCM Pilot is to assist at-risk women and infants access medical and social support services, through an intensive case management and outreach model. When CMCM is fully implemented, it will be administered by Syracuse Community Health Center. The five pilot outreach workers are stationed at Crouse Irving Memorial Hospital, SUNY Health Science Center, St. Joseph's Hospital, Syracuse Community Health Center and MANOS/Vincent House.

4. New York State Community Health Worker Grant
   This grant funds intensive community-based outreach and case finding activities in the two highest risk areas of the City of Syracuse. Three outreach workers are assigned to the Hilltop area through PEACE, Inc and three are assigned to the Southwest Community Center.

5. Augmentation of Public Health Nursing Teams
   Public Health Social Work staff will work in conjunction with outreach workers to address a broad range of social service needs for high risk nursing team clients.

6. Case Management Provider Group
   Health Department Commissioner James Miller, MD. and Social Services Commissioner Robert Stone have established a coordinating group comprised of local human service agency directors with experience in case management. The aim of this group is to determine what services are currently available for the target population, to coordinate these services and decide how best to utilize new outreach and case management workers.

7. Access Center
A computerized database is under development with the assistance of Syracuse University. The system will track all at-risk women and infants to assure timely outreach intervention, maintain a case file on each tracked individual to facilitate case management and collect and analyze data for future planning purposes. (See Attachment B)

## B. MEDICAL

1. PCAP Transition
See description above - III.A.1

2. Opening of Family Health Services/Integrated Clinic
This clinic, held at the Civic Center, consolidates services at one site to provide increased accessibility to the full array of County Health Department clinic services.

3. Drug and Alcohol Services
Through the Department of Mental Health, the Outpatient Drug Clinic at Crouse Irving Memorial Hospital provides individual and group counseling for pregnant and parenting women. Additionally, The Department of Mental Health is proposing the expansion of Syracuse Community Health Center's Alcohol & Substance Abuse Services to increase the number of people served. These programs will accept referrals to provide counseling, to increase substance abuse awareness and to improve maternal and infant health outcomes. Pending the results of the Department of Health's surveillance program, the Departments of Health, Mental Health and Social Services will develop programs to ensure rehabilitative services.

4. Fetal Alcohol Syndrome (FAS) Grant
The FAS Prevention of Disabilities Project has established a community-wide Task Force. The purpose of this Task Force is to reduce the incidence of disabilities resulting from maternal drug and alcohol consumption. Task force activities include data collection and analysis, professional and public education and service and referral coordination.

## C. FAMILY AND SOCIAL SUPPORTS

1. Outstationing for Medicaid Intake
   To assure Medicaid coverage for eligible low income pregnant women and infants, Medicaid intake workers will be assigned to work at the major provider sites of prenatal and newborn care services. Presently they are outstationed at St. Joseph's Hospital, Syracuse Community Health Center, SUNY Health Science Center and the Onondaga County Health Department PCAP clinics.

2. Outstationing for Women, Infant & Children's Program (WIC) Intake
   To assure early admission into WIC for high risk pregnant women, WIC intake workers are assigned to work at the major provider sites of prenatal care and newborn care services. Presently they are outstationed at St Joseph's Hospital and Crouse Irving Memorial Hospital. Additional outstationing is planned.

3. Transportation
   The Department of Social Services is currently evaluating funding options and modes of transportation for at-risk women and infants to medical appointments. A combination of taxis, bus tokens, agency vans and paid mileage for outreach worker vehicles will be utilized.

4. Child Care for Clinical Purposes
   The Department of Social Services is considering expanding child care services for clinic purposes. It is yet to be determined whether a centralized site or a number of individual sites will be designated for child care.

5. Drug & Alcohol Services
   See description above - III.B.3

6. Domestic Violence
   The Department of Social Services contracts with Vera House and Dorothy Day House to provide support services for battered women. Vera House also operates a new program known as Alternatives: Building Non-Violent Relationships. This is an educational program for batterers. While many participants volunteer for this program, others are court mandated.

Child Abuse and Neglect
The Department of Social Services contracts with numerous agencies including Catholic Charities, Child and Family Services, and The Salvation Army to provide a variety of supportive and rehabilitative services for families at risk of child abuse or neglect. The Parents and Children Together (P.A.C.T) Program is a new program now available as a preventive service within the Department of Social Services Children's Division. This innovative program is designed to provide crisis intervention services to families with children at imminent risk of placement. The Department of Social Services will evaluate existing programs to determine whether expansion or further development of new services is warranted.

## D. ASSESSMENT & EVALUATION

1. Surveillance Activities
The Bureau of Surveillance & Statistics in the Health Department will undertake additional activities associated with furthering our understanding of the infant mortality problem and associated risk factors.

a. Infant Mortality Review
This program will conduct comprehensive reviews of all infant deaths in Onondaga County. Included in this process is an interview with the mother and analysis of medical and human service records. Based on the findings of these studies, a Community Review Team will propose interventions and policies to address any preventable factors associated with infant mortality.

b. Drug and Alcohol Surveillance
Through surveys, analysis of anonymous drug screen specimens, and indirect measures, the Surveillance program will attempt to characterize the nature and extent of substance abuse during pregnancy as a basis for additional program planning efforts.

c. Analysis of Vital Records Information
A computerized information system is planned for the Vital Records office. This system will allow more timely and more complete analyses of information from birth and death certificates. By reporting on low birth weight and other high risk births more quickly, the system will also serve as the basis for more timely referrals for public health nursing interventions.

2. Access Center
   See description above - III.A.7

## IV. OTHER KEY VARIABLES

The Action Plan outlined above is designed to address many of the leading risk factors associated with infant mortality. Unfortunately, there are many additional variables that must be confronted before this community will realize a significant decrease in infant mortality rates and in discrepancies among racial groups for these rates. The following list, although not inclusive, represents several issues outside of the scope of current Onondaga County Departments of Health and Social Services activities. Further study and comprehensive intervention are warranted in each of these areas.

### A. HUMAN SERVICE FACTORS

1. Number of Physicians Accepting Medicaid
2. Cultural Sensitivity Training For All Human Service Providers
3. Waiting Times & Conditions For Clinic Visits
4. Continuity of Care

### B. ECONOMIC DEVELOPMENT

1. Employment Opportunities
2. Job Training
3. Education
4. Housing

## V. COMMUNITY OBJECTIVES

The Departments of Health and Social Services with consultation from Mental Health have established the following five and ten year objectives (See Table on Page 9). The County assumes a leadership role, and the current action plan will play an integral part in this fight. However, achievement of these objectives will depend on a community wide effort to battle infant mortality. The community at large must be willing to expend time, energy, and resources in coordinated fashion. Civic organizations, educational institutions, churches, neighborhood associations, private industry and all human service providers must share responsibility for improving the medical and social conditions that result in infant mortality. In five years time, the County will reassess these objectives based on the success of the current action plan as well as community initiatives.

### DEFINITIONS OF TERMS

**Infant Mortality Rate:** Assesses the extent of infant (children up to one year of age) deaths in a population. The infant mortality rate (IMR) is calculated as the number of infant deaths divided by the number of births in that population in the same year. This quantity is multiplied by 1,000 so that the IMR can be read as the "number of infant deaths per 1,000 live births." When an IMR is used for a specific population, both the number of deaths and the number of births is specific to that population. For example, the infant mortality rate for white infants in Syracuse is calculated as the number of deaths of white infants born to Syracuse residents, divided by the number of white infants born to Syracuse residents.

**Low Birthweight:** Infants which weigh less than 2500 grams (i.e. 5.5 lbs.) at birth are classified as "low birthweight" infants.

**Late Entry to Prenatal Care:** Women who either initiate prenatal care in the last trimester (months 7 through 9) of pregnancy are considered to have received "late prenatal care". This group is usually combined with women who received no prenatal care in a "Late or No Prenatal Care" category.

## *COMMUNITY OBJECTIVES*

| | Current Reference (1) | Objectives | |
|---|---|---|---|
| | | 5-Year (2) | 10- Year (3) |
| ***LATE or NO PRENATAL CARE*** | | | |
| Onondaga County Total | 2.2% | < 3.2% | 1.0% |
| Syracuse Total | 3.4% | * | 1.0% |
| City Minority | 5.1% | * | 1.0% |
| ***% LOW BIRTH WEIGHT BIRTHS*** | | | |
| Onondaga County Total | 6.4% | < 5.9% | 5.0% |
| Syracuse Total | 8.5% | < 7.7% | 5.0% |
| City Minority | 13.3% | < 9.9% | 5.0% |
| ***SUBSTANCE ABUSE by PREGNANT or PARENTING WOMEN*** | | | |
| Onondaga County Total<br>Syracuse Total<br>City Minority | Unknown at this time. | Sub. Abuse surveillance system ∀ | Reduce by 20% from 1995 |
| ***INFANT MORTALITY RATE*** | | | |
| Onondaga County Total | 10.5 | < 9.1 | 7.0 |
| Syracuse Total | 15.2 | < 12.6 | 7.0 |
| City Minority | 27.3 | < 17.6 | 7.0 |

(1) "Current Reference" values are the local averages for 1985-1987.

(2) Five-year objectives are intended to have our area be better than or equal to comparable areas in New York state. The Onondaga County objective is the overall rate for Upstate New York (i.e., NYS except New York City). Syracuse objectives are calculated as the average of rates for Buffalo, Rochester, and Albany. The objectives are the rates for these areas in 1995. Shown here for reference purposes are the rates for these areas in 1985-1987.

Five-year objectives for minority populations are designed to reduce the racial differential by 50% in five years. Ten year objectives are to eliminate racial differences altogether.

(3) Ten-year objectives are taken from the U.S. Surgeon General's "Year 2000 Objectives for the Nation", or are derived independently where national objectives are lacking.

* Data for calculation of objective not yet available, pending data request from NYSDOH.

∀ The objective is to have a surveillance system in place to assess the extent of substance abuse in this population, and to have reliable estimates of the prevalence by 1995. This value would serve as the basis for the 10-year objective.

ATTACHMENT F

## ONONDAGA COUNTY
## INFANT MORTALITY DATA
## FACT SHEET

**Phase I**

- Overall infant mortality rate for the County is not elevated
  (1985-1987 rate = 10.4 deaths per 1,000 live births; NYS average = 10.7; Upstate Average [i.e., NYS excluding NYC = 9.1)
- Rate for the City of Syracuse is highest of 27 cities of comparable size
  (1987 data: Syracuse= 17.8; Second highest in survey: Raleigh, NC = 16.4 Survey by R. Lagoe, Ph.D., Hospital Executive Council)
- Rate for Black infants is approximately three times the rate for White infants
  (1985-87 City averages: White=9.3, Black= 30.7)
- Rate for Black infants is higher than 18 large urban centers, based on 1985 data
  (Syracuse data based on 1984-86 average [= 27.2] ; Second highest in survey: Boston, MA = 25.3; Data from Children's Defense Fund)
- Neonatal (i.e., birth to one month) mortality rate (NMR) for Black infants is about two times that for Whites (1984-1986 City data: White NMR = 6.2, Black NMR= 15.0)
- Postneonatal (i.e., one month to one year) mortality rate (PNMR) for Black infants increased from 1982-1987, to be three to four times that of Whites (1981-1983 City data: White PNMR = 4.1, Black PNMR= 7.5; 1984-1986: White PNMR = 3.1, Black PNMR= 12.8)

**Phase II**

- Causes of neonatal deaths are associated primarily with prematurity or congenital anomalies. The single largest cause of Postneonatal Mortality is Sudden Infant Death Syndrome. No obvious differences in causes of death exist between the races.
- Infant mortality is highest in the West, Southwest, and East Fayette neighborhoods within Syracuse.
- Primary influences on Infant Mortality are low birth weight, premature delivery, and late/no entry to prenatal care.
- Influences of Black race, poverty, and teenage motherhood are mediated through the primary influences.
- The percentage of Black births with Late/No prenatal care have risen sharply between 1981 and 1987, from 2.0% (1981-82 avg.) to 5.0% (1986-87 avg.).
- Race and poverty have statistically independent influences on infant mortality.
- Mortality for Low Birth Weight Black infants is 1.7 times that for LBW White infants. For normal weight infants the Black mortality rate is 3.9 times as high.

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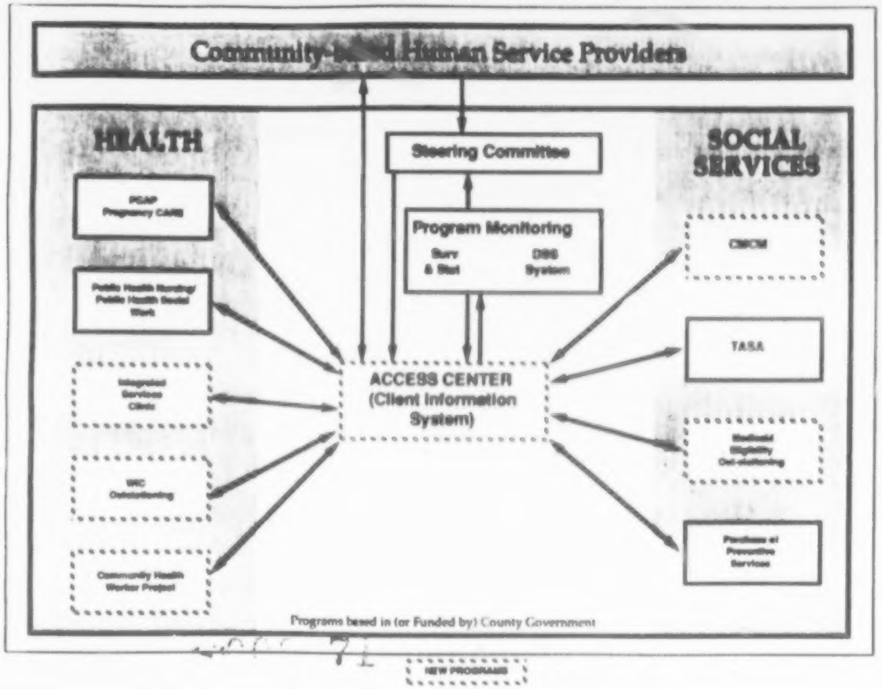
[1] Unless otherwise noted, all data were provided by the NYS Health Department Bureau of Vital Statistics. Analyses were conducted by the Onondaga County Health Department, Bureau of Surveillance and Statistics

# Development & Coordination of Services to Reduce Infant Mortality


Community-based Human Service Providers
HEALTH
SOCIAL SERVICES
Steering Committee
Program Monitoring
Surv & Stat
DSS System
ACCESS CENTER (Client Information System)
PCAP Pregnancy CARE
Public Health Nursing/ Public Health Social Work
Integrated Services Clinic
WIC Outstationing
Community Health Worker Project
CMCM
TASA
Medicaid Eligibility Out-stationing
Purchase of Preventive Services
Programs based in (or Funded by) County Government
NEW PROGRAMS

# Infant Mortality in Onondaga County, 1980-1987
## II.: Analysis of Risk Factors

Prepared by

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Bureau of Surveillance and Statistics
Edward C. Waltz, Ph.D., Director
Donald A. Cibula, Project Analyst

## Abstract

The risk of a black infant dying was triple that of a white infant born in Onondaga County, NY during 1981-1987. Evaluation of the causes of death fails to explain this disparity; the causes are diverse, lack clear-cut medical remedies, and do not differ appreciably between black and white infants. Analyses of socioeconomic correlates of infant mortality rate (IMR) were carried out. The results, which are the focus of this report, establish some basis for an informed opinion about why these racial differences in IMR exist. Comparison of tract-level data between sets of census tracts with similar poverty levels but different racial composition indicates that IMR is significantly higher in poor areas of Syracuse with high proportions of black residents relative to comparably poor, predominantly white areas. A subsequent, more comprehensive analysis of likely IMR correlates using tract-level data revealed that low birth weight (LBW), late/no prenatal care and prematurity are the primary associates of differences in IMR among Onondaga County census tracts. Comparisons of black and white infants using birth certificate data indicate that on average, black infants are at significantly greater risk of LBW, late prenatal care, and prematurity than are their white counterparts.

### Introduction

The black infant mortality rate (IMR) in Syracuse and Onondaga County, New York is disturbingly high; the preceding paper in this series established that the overall rate was 27.4 deaths per 1000 live births during 1981-1987. Compared with 18 large cities including New York, Boston, Chicago and Detroit, Onondaga County has the highest black infant mortality rate of all. Because the mortality rate for white infants in this county is relatively low (9.2/1000 for the same period), the risk to black infants is nearly triple that of whites. Thus the black:white risk ratio for Onondaga County is also the highest of any in the aforementioned group of cities. Beginning in 1983, much of the elevated risk to blacks has been concentrated in the postneonatal period, i.e. from 28 days to one year of age.

This paper describes additional analyses in which we examine the causes of infant deaths and evaluate some potential correlates of infant mortality. Our purpose is to identify those socioeconomic and medical conditions which are most strongly associated with infant mortality in Onondaga County and to provide information that will assist in planning effective strategies for intervention.

### Causes of Mortality

As a point of departure, causes of infant mortality were examined on the assumption that they may indicate underlying medical and social risk factors. Results of this investigation are presented in Figure 1. In general, the causes of death are diverse, somewhat nebulous, and lack clear-cut medical remedies (Figure 1). Furthermore, the pattern of causes is strikingly similar for both races, particularly during the postneonatal period, which is especially risky for black infants. For example, SIDS, a category representing undiagnosed causes of death even after an autopsy is performed, accounts for approximately half of the deaths of both black and white infants during the postneonatal period (Figure 1). Thus, this method of analysis failed to identify any causes disproportionately represented in blacks that might have pointed to unique medical or socioeconomic risk factors among the deceased black infants.

### General Influences on IMR: Race and Poverty

Abundant evidence in larger studies of the U.S. population indicates that non-white race and low socioeconomic status are tightly linked, and are correlated with elevated IMR. Therefore, in evaluating possible explanations for the large disparity in mortality rates between black and white infants in Onondaga County, it becomes important to determine if race is simply a proxy for income. An alternative explanation posits that racial differences in risk factors other than income also are involved, and they compound the already high risk faced by the poorest segment of our community. Obviously, distinguishing between these alternatives is important in tailoring effective public health intervention strategies.

Analysis of risk factors that involve socioeconomic status could not be conducted using information from individual birth or death certificates, because poverty indices can not be obtained from these records. Instead, we used average data for census tracts, including the racial makeup of tracts and their poverty status in 1979, which were obtained from the 1980 U.S. Census. Elapsed time between the Census and the collection of the IMR data may contribute to measurement error, since some temporal changes in poverty status undoubtedly occur. Nevertheless our technique is justified, in part because the overall pattern of population distribution has not changed appreciably. Furthermore, the main effect of this time lag is to make it more difficult to demonstrate any statistical association between the 1979 socioeconomic data and the IMR and medical risk factor data. Under such adverse conditions, any association we might find would be a conservative estimate.

Multiple linear regression was used as the first test of the hypothesis that race is a proxy for income and that factors associated with socioeconomic status eclipse race as predictors of IMR. A result consistent with this hypothesis would be to find that a regression model containing both a racial and an economic index has no greater ability to predict IMR than an alternative model containing only the economic index. In fact, the actual results of the multiple linear regression analysis are just the opposite; the percentage of black households per census tract is a strong, positive predictor of IMR on a per tract basis. In contrast, percentage of households below poverty level does not provide additional, unique information which significantly strengthens the predictive ability of the regression (Table 1). It should be noted here that we are not disavowing the influence of socioeconomic factors on IMR. Instead, we suggest that both race and poverty probably are involved, but this regression analysis indicates that factors associated with racial composition show a tighter statistical relationship.

A second analytical method was used to check and to expand upon the results of the regression analysis. In this method, we selected seven pairs of relatively impoverished tracts in Syracuse, with each pair having one tract with a substantial black population, and the other being predominantly white . Each pair was matched internally for the percentage of households per tract that fell below poverty level in the 1980 census. We checked the efficacy of our selection process and found no statistical difference between the two groups in terms of poverty but also found that the planned difference between them in racial composition was statistically real (Figure 2). Our regression results suggested that race has important effects beyond its linkage with poverty status. It follows that IMR should be higher in tracts with high percentages of black residents. On the other hand, if race acts solely as a proxy for income, then IMR should not differ between the groups, because they were equivalent with respect to the poverty index. The actual results are that during the period 1981-1983, IMR is significantly higher in poor areas of Syracuse with high proportions of black residents relative to comparably poor, predominantly white areas (Figure 2). This finding confirms the results of the regression analysis and suggests again that race or factors linked with race are important correlates of infant mortality.

### Delving Deeper: Assessing Some Specific Risks

A logical next step was to shift the focus of our investigation away from the general influences of race and poverty and evaluate some more narrowly-defined IMR risk factors. We chose seven variables for study that meet two criteria: 1) they have been implicated as risks in some larger studies, and so they are likely to be important locally; and 2) local tract-based data are available. The variables chosen (see Table 2 for definitions) are: teenage motherhood, low birth weight, prematurity, delayed or no prenatal care, racial composition of tracts, proportion of births to black mothers, and poverty. The multiple linear regression technique was used to determine which of these putative factors is/are most strongly associated with differences in IMR among census tracts. Alternatively phrased, the question becomes: Which of these risk factors provides the most information to predict the rate of infant mortality for a particular census tract? An answer to this question should be helpful in developing plans to combat infant mortality. Results of the multiple regression analysis suggest that low birth weight, prematurity, and late or no prenatal care are the most valuable predictors of infant mortality (Table 2 and Figure 3). A linear combination of these three factors accounts for nearly half of the variation in IMR among Onondaga County census tracts ($r^2$=0.46, F[3,118]=33.6, P=0.0001). Given the inherent limitations of this technique, this is a remarkably strong association. Supplementary analysis indicated that all seven of these variables are tightly correlated, both among themselves and with IMR (Table 3). However, the regression results also indicate that poverty, maternal age and measures of racial composition per tract do not provide additional, unique information which would significantly improve our ability to predict IMR in Onondaga County census tracts. Another way of stating this result is to say that a model containing information on all seven of these risk factors is no better at predicting IMR outcomes than is a model containing only tract-level data on low birth weight, late/no entry into prenatal care and prematurity.

### Racial Comparison of Risk Factors

In the course of this report, our focus has shifted from the rather broad, inclusive risks of race and poverty towards consideration of more narrowly-defined factors such as birth weight and entry into prenatal care. This reductionist approach may be further served by contrasting IMR risk factors obtained from the individual birth records of white and black infants. Since IMR is significantly higher for blacks and since low birth weight, prematurity and late/no prenatal care are related to IMR locally, one would predict that these risk factors should be greater for black infants. Our analyses indicate that on average, black infants were at higher risk than white ones with respect to every factor considered during the period 1985-1987 (Figure 4). Black mothers, on average, were younger and they entered prenatal care significantly later than their white counterparts (Figure 4). The percentage of black mothers in Onondaga County receiving late/no prenatal care has increased substantially since 1981, and the black:white ratio for this risk factor was 3.4:1 in 1987 (Figure 5). In addition, black babies born during 1985-1987 weighed less and they had shorter gestational periods than white infants (Figure 4). These findings provide a basis for an informed opinion about why the disparity between white and black IMR exists. It should be noted however, that the results of these analyses do not establish causation, only statistical association.

### Analysis of Weight-specific IMR

When infant mortality rates are categorized by race and birth weight classes, it can be seen that black infant mortality is significantly higher than the rate for white infants for individuals weighing less than 2500 gm at birth (Table 4). This, in combination with the finding that there is a higher proportion of black births below 2500 gm (Table 4), lends further support for suggesting that prematurity and low birth weight are important contributors to the unacceptably high rates of black infant deaths in Syracuse and Onondaga County.

### Spatial Patterns of IMR and Risk Factors

The series of Syracuse neighborhood maps (Figures 7-14; see Figure 7 for OCHD-defined neighborhood boundaries) show the spatial pattern of IMR and risk factors within the city limits and provide an effective visual summary of the the information described previously in statistical terms. These maps indicate that areas of the city with high IMR (Figure 8) generally coincide with areas having late or no entry into prenatal care (Figure 9), prematurity (Figure 10), and low birth weight (Figure 11). The areas with the highest IMR and associated risk factors are the near south and west neighborhoods, as well as the series of census tracts extending along East Fayette Street. These areas generally have sizeable black and poor populations (Figures 12 and 13) with relatively high rates of teenage pregnancy (Figure 14). Knowledge of this spatial pattern of IMR and its attendant risk factors should prove to be valuable in planning methods and selecting target areas for intervention.

## Discussion and Conclusions

We have summarized the results of the regression analyses in Figure 15, and have suggested likely (to us) directional associations between variables. It is important to note that regression analysis measures only statistical association-- not causal relationships. Based on the extensive literature available on this subject, we suggest here some underlying causal relationships that may explain these statistical associations. The main result depicted here is that only the primary correlates contribute significantly to the explanation of variation among tract level IMR. Among the primary correlates, both premature birth and low birth weight are likely to be results of late (or no) entry into prenatal care; and low birth weight certainly is a direct result of short gestation. Causal relationships among the secondary correlates are less easily inferred, so we have merely drawn lines interconnecting Poverty, Black Race, and Teenage Pregnancy.

Caution must be used in interpreting these (or any multiple regression) results. While the technique is very powerful, it is no more powerful than the information available for analysis. A number of potentially important variables are not available for these analysis, including consistency of prenatal care (i.e., the number of prenatal visits, not merely the timing of the first visit), measures of hospital or pediatric care, parenting skills, and family status (e.g., the numbers of supporting adults in the household). Apparent influences of any variables we included could be serving as a proxy, entirely or in part, for these or other unmeasured variables. The independent influence of Late or No Entry into Prenatal Care is a good example. Its statistically independent correlation suggests influences other than those mediated through Low Birth Weight or Prematurity. It might be that late care results in developmental deficits not reflected in birth weight. It might also be that late entry to care reflects poor medical care or access; perhaps the essential, but unmeasured, influence on IMR is inadequate pediatric care. We urge considerable circumspection in the interpretation of these results.

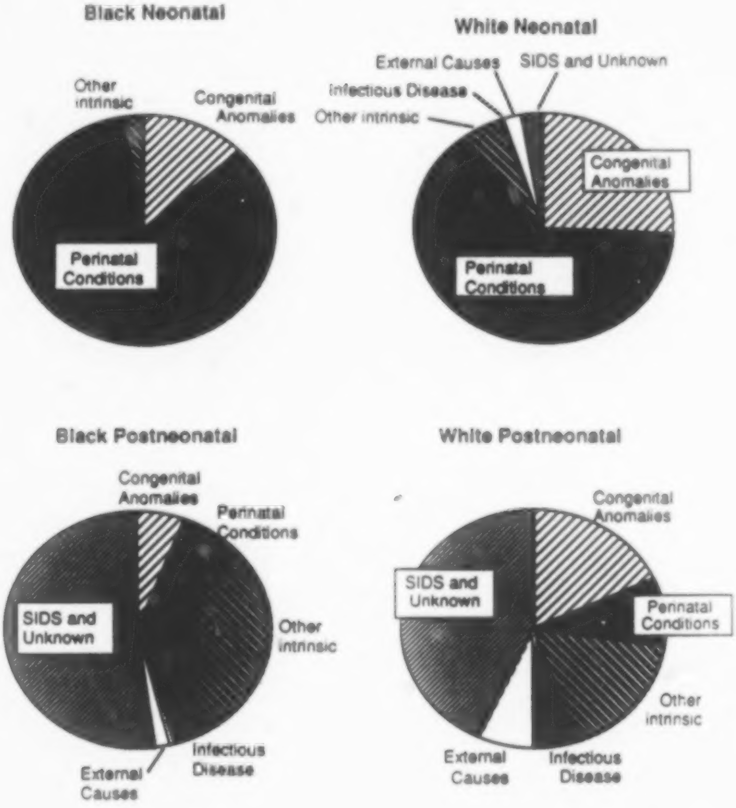
Although teenage pregnancy does not explain a significant portion of variation among census tracts in IMR in our community, the available literature suggests that it could play at least a supplemental role in the risk process. The annual percentage of black births to females aged 10 through 19 has fluctuated between 25.6% and 28.8% during 1981-1987, at roughly 3.5 times the comparable rate for white mothers (Figure 6). As we pointed out in the previous report, 24% of all black postneonatal deaths occur when the mother is 17 years old or younger, while only 14% of the live births are to mothers in this age group.

Perhaps the most important results of all of these analyses are the indications to the health care delivery system as to where efforts should be directed to ameliorate the local infant mortality problem. The absence of clearly treatable causes of death suggest that no medical "Magic Bullet" solution exists. Only a general, substantial improvement in the maternal and child health system is likely to have any impact. Two of the potential influences depicted in Figure 15, Entry to Prenatal Care and Teenage Pregnancy, can be targeted directly, with the expectation that problems of low birth weight and prematurity can be lessened as a result. The maps in Figures 9 and 14 suggest areas where these intervention efforts are needed most critically-- the south and west sides of Syracuse, as well as the East Fayette Street area.

Of course, the fundamental underlying problem of racially-biased poverty should not be ignored here merely because it is beyond the scope of the health care system's direct domain of influence. A permanent solution requires a community-wide effort involving not only health care, but also the social services, education, and economic systems if Onondaga County is to remedy this profoundly troubling problem.

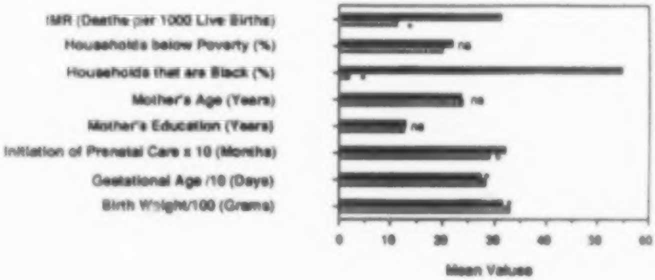
Figure 1

## Causes of Infant Deaths Onondaga County Residents, 1981-1986



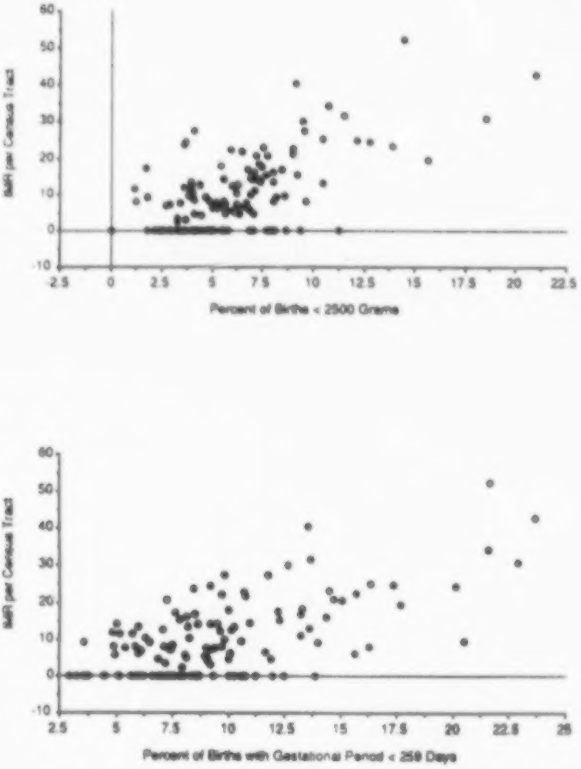
Prepared by Onondaga County Health Department
Bureau of Surveillance & Statistics

**Figure 2.** Mean values of IMR and putative risk factors for selected Syracuse census tracts with high percentages of black residents (>40%, represented by solid bars) or white residents (>92%, represented by hatched bars). Tracts from each group were matched for percentage of households below poverty. Means are presented on a per tract basis. Asterisks indicate significant differences between the groups, as determined by Wilcoxon Two-Sample tests, while "ns" indicates non-significant differences. Based on data from New York State Vital Records for 1981-83.



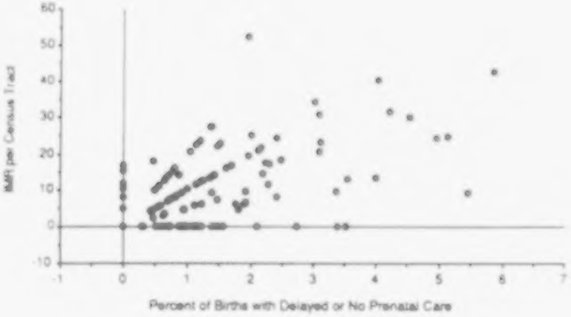
Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics

**Figure 3. IMR vs. Selected Risk Factors.** IMR per census tract plotted against risk factors selected through multiple multiple regression analysis. Data are for Onondaga County tracts, 1985-1987. Tracts in which there were less than 50 births during this period are excluded.



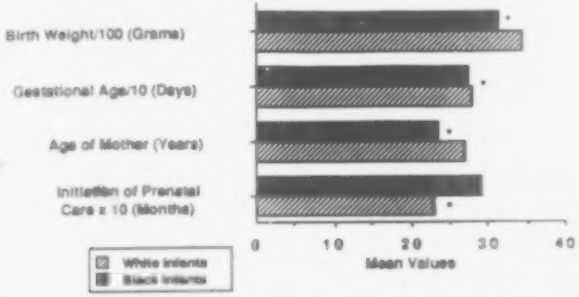
Prepared by: Onondaga County Health Department, Bureau of Vital Statistics
Data source: New York State Vital Records.

**Figure 3 Con't. IMR vs. Selected Risks.** IMR per census tract plotted against risk factors selected through multiple multiple regression analysis. Data are for all Onondaga County tracts, 1985-1987. Tracts in which there were less than 50 births during this period are excluded.



Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data source: New York State Vital Records

**Figure 4. Racial Comparison of Risk Factors, Birth Certificate Data.** Mean values of mortality risk factors for white and black infants born to Onondaga County residents during 1985-1987.

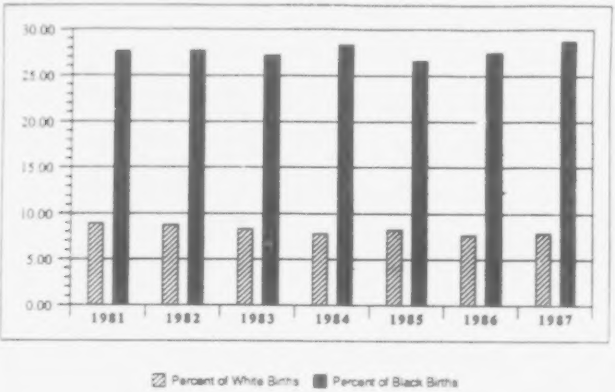


Asterisks indicate significant differences between the races, as determined by t-tests.

| Variable | Race | Median | Mean | Std. Dev. | N |
|---|---|---|---|---|---|
| Birth Weight (Grams) | W | 3459 | 3425.0 | 593.6 | 18039 |
| | B | 3204 | 3119.5 | 672.7 | 2667 |
| Gestational Age (Days) | W | 281 | 280.3 | 19.6 | 17832 |
| | B | 276 | 273.0 | 26.2 | 2612 |
| Mother's Age (Years) | W | 27 | 27.1 | 5.2 | 18046 |
| | B | 23 | 23.4 | 5.6 | 2669 |
| Initiation of Prenatal Care (Months) | W | 2 | 2.3 | 1.2 | 17971 |
| | B | 3 | 2.9 | 1.5 | 2652 |

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics

**Figure 5. Births to Teenage* Mothers by Race and Year
Onondaga County, NY 1981-1987**

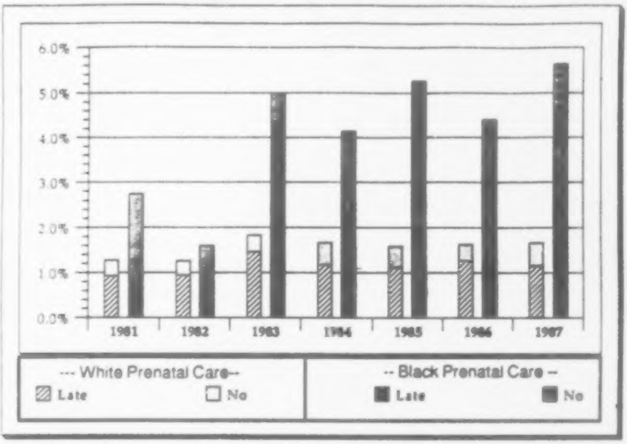


|  | — Race: WHITE — |  | — Race: BLACK — |  |
|---|---|---|---|---|
| YEAR | Number | Percent | Number | Percent |
| 1981 | 505 | 8.89 % | 211 | 27.62 % |
| 1982 | 511 | 8.74 % | 226 | 27.70 % |
| 1983 | 496 | 8.33 % | 218 | 27.18 % |
| 1984 | 476 | 7.76 % | 232 | 28.26 % |
| 1985 | 515 | 8.22 % | 234 | 26.53 % |
| 1986 | 464 | 7.62 % | 251 | 27.46 % |
| 1987 | 448 | 7.88 % | 251 | 28.75 % |

Data Source: New York State Vital Records
Analysis and Graph prepared by Onondaga County Health Department
Bureau of Surveillance and Statistics

* Births to females age 10 through 19

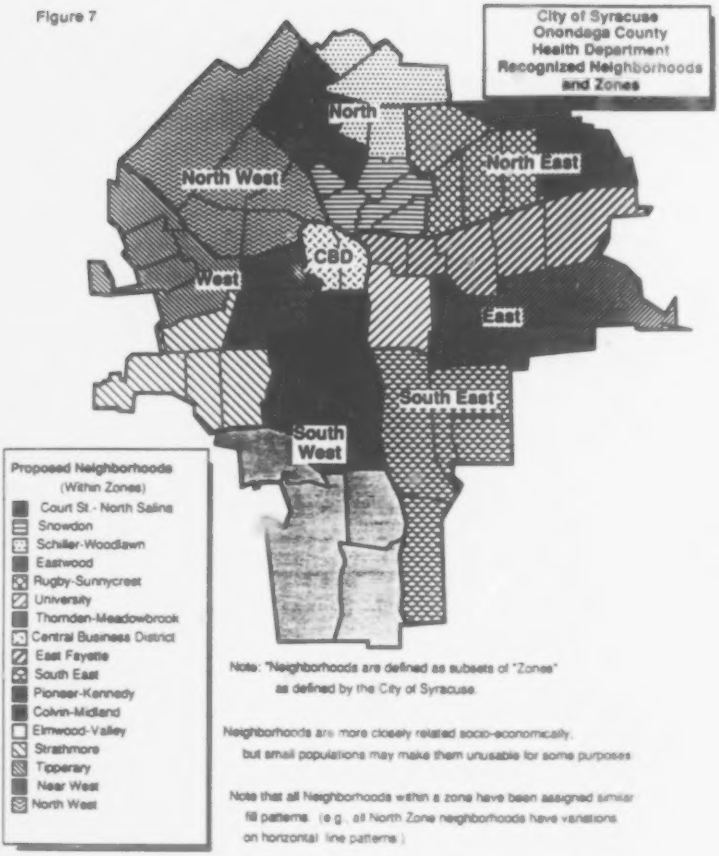
Figure 6 **Entry to Prenatal Care by Race and Year**
**Onondaga County, NY 1981-1987**



|  | —— Race: WHITE — |  |  | — Race: BLACK — |  |  |
|---|---|---|---|---|---|---|
| YEAR | Late PNC | No PNC | Late/No | Late PNC | No PNC | Late/No |
| 1981 | 0.9% | 0.4% | 1.3% | 0.9% | 1.8% | 2.8% |
| 1982 | 0.9% | 0.3% | 1.3% | 1.1% | 0.5% | 1.6% |
| 1983 | 1.5% | 0.4% | 1.8% | 4.4% | 0.6% | 5.0% |
| 1984 | 1.2% | 0.5% | 1.7% | 3.4% | 0.7% | 4.1% |
| 1985 | 1.1% | 0.5% | 1.6% | 3.9% | 1.4% | 5.3% |
| 1986 | 1.3% | 0.4% | 1.6% | 2.8% | 1.7% | 4.4% |
| 1987 | 1.2% | 0.5% | 1.7% | 4.6% | 1.0% | 5.6% |

Data Source: New York State Vital Records
Analysis and Graph prepared by Onondaga County Health Department
Bureau of Surveillance and Statistics

Figure 7


City of Syracuse
Onondaga County
Health Department
Recognized Neighborhoods
and Zones
North
North West
North East
CBD
West
East
South East
South
West
Proposed Neighborhoods
(Within Zones)
Court St. - North Salina
Snowdon
Schiller-Woodlawn
Eastwood
Rugby-Sunnycrest
University
Thornden-Meadowbrook
Central Business District
East Fayette
South East
Pioneer-Kennedy
Colvin-Midland
Elmwood-Valley
Strathmore
Tipperary
Near West
North West

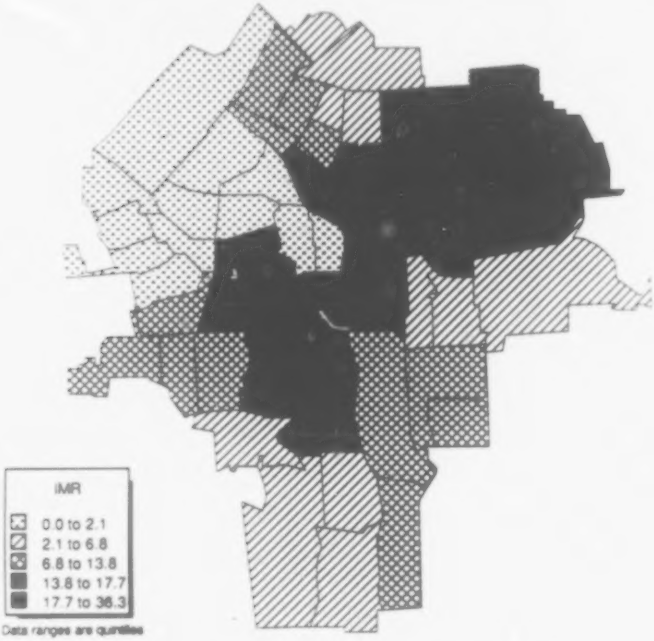
Note: "Neighborhoods are defined as subsets of "Zones" as defined by the City of Syracuse.

Neighborhoods are more closely related socio-economically, but small populations may make them unusable for some purposes.

Note that all Neighborhoods within a zone have been assigned similar fill patterns. (e.g., all North Zone neighborhoods have variations on horizontal line patterns.)

Figure 8

INFANT MORTALITY RATE
City of Syracuse "Neighborhoods", 1985-1987


IMR
▨ 0.0 to 2.1
▨ 2.1 to 6.8
▨ 6.8 to 13.8
■ 13.8 to 17.7
■ 17.7 to 36.3
Data ranges are quintiles

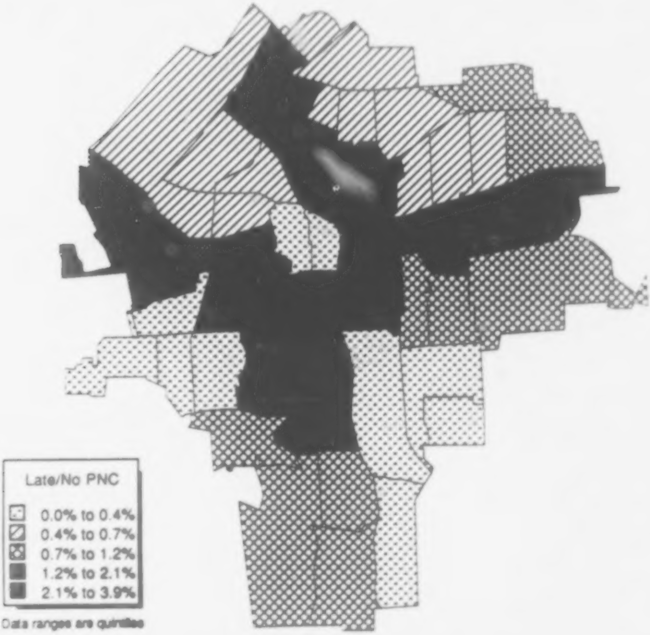
Note: "Neighborhoods" are defined as contiguous groups
of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics

Figure 9

## LATE/NO PRENATAL CARE

City of Syracuse "Neighborhoods", 1985-1987



Data ranges are quintiles

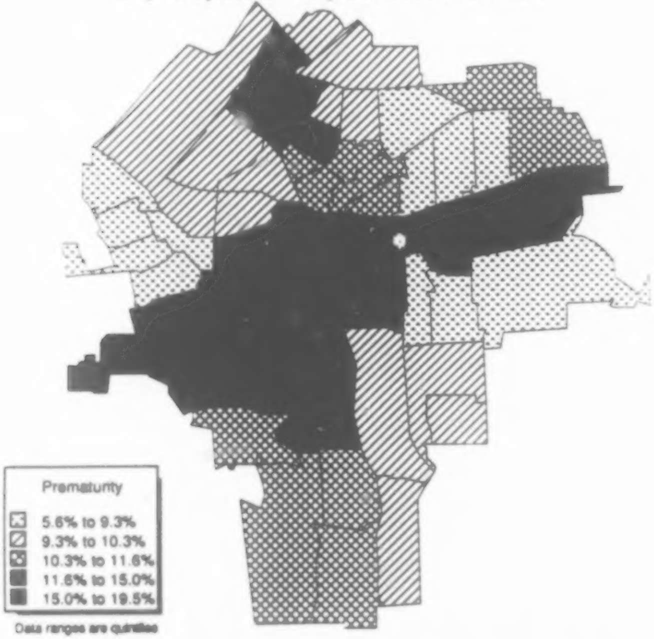
Note: "Neighborhoods" are defined as contiguous groups of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics

Figure 10

## PREMATURITY: Percentage of Births with Gestational Age Less than 37 Weeks

City of Syracuse "Neighborhoods", 1985-1987


Prematurity
5.6% to 9.3%
9.3% to 10.3%
10.3% to 11.6%
11.6% to 15.0%
15.0% to 19.5%
Data ranges are quintiles

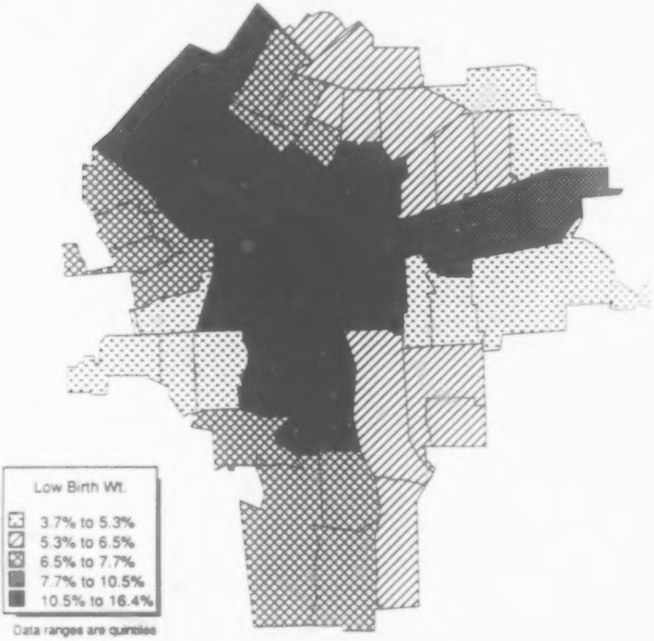
Note: "Neighborhoods" are defined as contiguous groups of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics

Figure 11

## LOW BIRTH WEIGHT

### City of Syracuse "Neighborhoods", 1985-1987


Low Birth Wt.
3.7% to 5.3%
5.3% to 6.5%
6.5% to 7.7%
7.7% to 10.5%
10.5% to 16.4%
Data ranges are quintiles

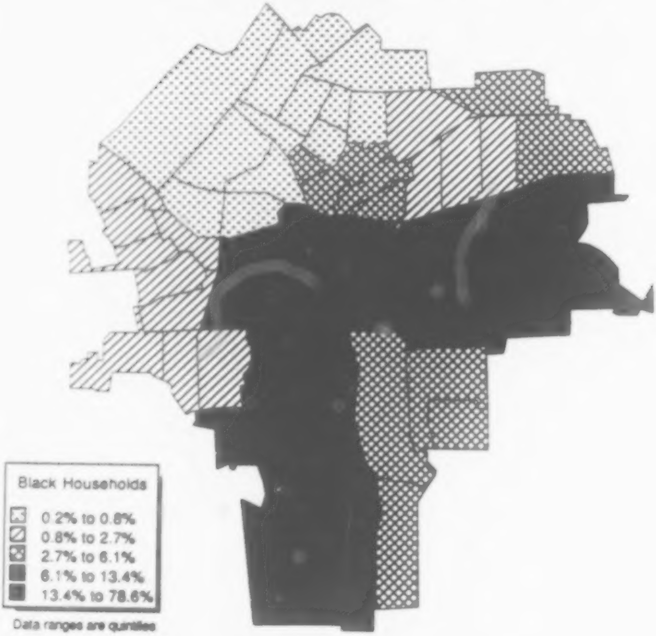
Note: "Neighborhoods" are defined as contiguous groups
of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics

Figure 12

## BLACK HOUSEHOLDS

### City of Syracuse "Neighborhoods", 1980


Black Households
0.2% to 0.8%
0.8% to 2.7%
2.7% to 6.1%
6.1% to 13.4%
13.4% to 78.6%
Data ranges are quintiles

Note: "Neighborhoods" are defined as contiguous groups of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

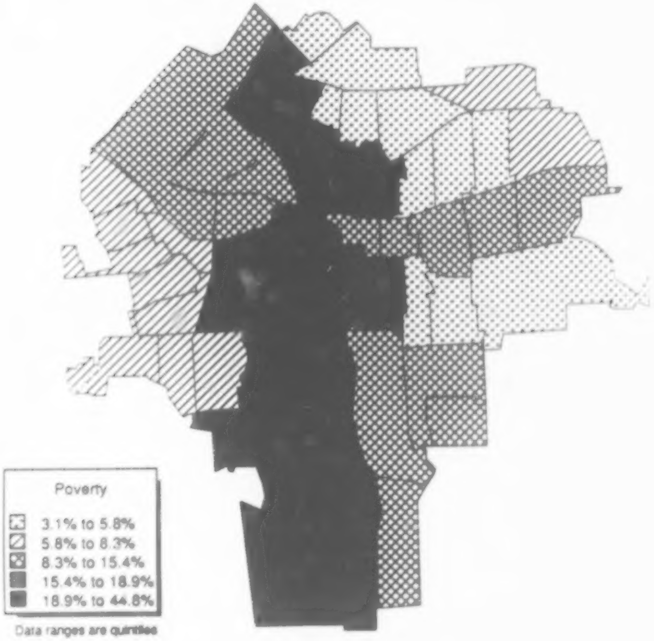
Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics and the 1980 U.S. Census

BEST COPY AVAILABLE

Figure 13

## POVERTY

### City of Syracuse "Neighborhoods", 1980



Data ranges are quintiles

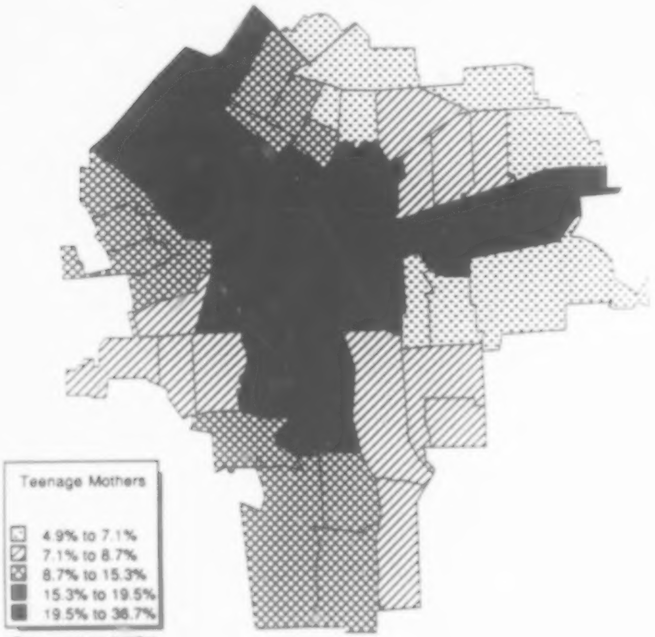
Note: "Neighborhoods" are defined as contiguous groups of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Bureau of Vital Statistics and the 1980 U.S. Census

Figure 14

## TEENAGE MOTHERS

### City of Syracuse "Neighborhoods", 1985-1987

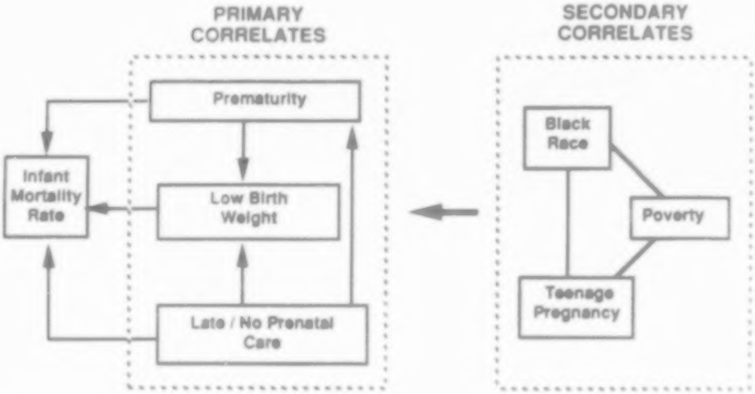

Teenage Mothers
▨ 4.9% to 7.1%
▨ 7.1% to 8.7%
▨ 8.7% to 15.3%
■ 15.3% to 19.5%
■ 19.5% to 36.7%

Data ranges are quintiles

Note: "Neighborhoods" are defined as contiguous groups
of (1980) census tracts which satisfy two criteria:
(1) the tracts are at least generally similar in socio-economic conditions
(2) they contained approximately 10,000 residents in the 1980 Census

Prepared by Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source New York State Bureau of Vital Statistics

**Figure 15. Network of associations among risk factors for infant mortality.** Primary correlates of IMR (prematurity, low birth weight and late/no prenatal care) were selected on the basis of multiple regression. All six correlates are significantly interrelated; the single, heavy arrow between the primary and secondary correlates is a simplified way to represent the fact that all secondary correlates are correlated with all primary correlates (see Table 3).


PRIMARY CORRELATES
SECONDARY CORRELATES
Prematurity
Infant Mortality Rate
Low Birth Weight
Late / No Prenatal Care
Black Race
Poverty
Teenage Pregnancy

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Based on Data Provided by New York State Bureau of Vital Statistics

**Table I. Multiple Regression I: Race and Income.** Summary of results of regression of IMR against an index of income and of racial composition per tract, for the periods 1981-1983 and 1984-1986.

| VARIABLE | Inclusion of Variable Significantly Improves Ability to Predict IMR? |  | Sample Size (n) |  | R-Square (%) |  |
|---|---|---|---|---|---|---|
|  | *1981-1983* | *1984-1986* | *1981-1983* | *1984-1986* | *1981-1983* | *1984-1986* |
| Percentage of Households Below Poverty per Census Tract | No | No | 55 | 56 |  |  |
| Percentage of Black Households per Census Tract | Yes | Yes | 55 | 56 | 23 | 26 |

Analysis includes Syracuse census tracts only.
R square represents the percentage of variance in IMR among tracts that is accounted for by intertract differences in the poverty index.

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data source: New York State Bureau of Vital Statistics and the 1980 U.S. Census

**Table 2. Multiple Regression II: Selected Risks For IMR.** Summary of results of multiple regression of IMR per census tract against the listed set of independent variables. A linear combination of the first three variables listed accounts for 46% of the variation in IMR among census tracts.

| Independent Variable | Derivation/Definition of Variable (on a per Census Tract Basis) | Inclusion of Variable Significantly Improves Ability to Predict IMR? |
|---|---|---|
| Low Birth Weight | Percentage of Births Less than 2500 gm. | Yes |
| Late/No Prenatal Care | Percentage of Births in which Prenatal Care Was Initiated During Third Trimester or not at All | Yes |
| Prematurity | Percentage of Births with Gestational Age less than 259 Days (37 Weeks) | Yes |
| Teenage Pregnancy | Percentage of Births that are to Teenage Mothers | No |
| Poverty | Percentage of Households that are Below Poverty (1980 Census) | No |
| Black Births | Percentage of Births that are to Black Mothers | No |
| Black Households | Percentage of Households that are Black (1980 Census) | No |

Data are for Onondaga County census tracts, 1985-1987. Tracts for which total live births during this period was less 50 individuals are excluded

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data source: New York State Bureau of Vital Statistics and the 1980 U.S. Census

**Table 3. Simple Correlations.** Matrix of all pairwise correlations among investigated variables. Values represent Pearson correlation coefficients. Every coefficient is statistically significant.

| | IMR | Prematurity | Low Birth Weight | Black Births | Black Households | Teenage Pregnancy | Late/No Pre-natal Care | Poverty |
|---|---|---|---|---|---|---|---|---|
| **IMR** | -- | 0.63 | 0.63 | 0.58 | 0.58 | 0.56 | 0.54 | 0.48 |
| **Prematurity** | | -- | 0.77 | 0.74 | 0.7 | 0.73 | 0.62 | 0.6 |
| **Low Birth Weight** | | | -- | 0.72 | 0.68 | 0.69 | 0.60 | 0.62 |
| **Black Births** | | | | -- | 0.94 | 0.78 | 0.56 | 0.64 |
| **Black Households** | | | | | -- | 0.78 | 0.55 | 0.64 |
| **Teenage Pregnancy** | | | | | | -- | 0.70 | 0.82 |
| **Late/No Prenatal Care** | | | | | | | -- | 0.54 |
| **Poverty** | | | | | | | | -- |

Sample sizes for the correlations range from 122 to 126.

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Health Department, Bureau of Vital Statistics and the 1980 U.S. Census

**Table 4. IMR by Race and Birth Weight Classes.** Infant mortality per 1000 live births to black and white residents of Onondaga County in 1985-1987, by birth weight classes.

| Birth Weight Class/Race | Total Births | Percentage of Births | Total Deaths | IMR | B:W Risk Ratio |
|---|---|---|---|---|---|
| **> 2500 gm.** | | | | | 3.9:1 * |
| *White* | 17,058 | 95 | 50 | 2.9 | |
| *Black* | 2,312 | 87 | 26 | 11.2 | |
| **< 2500 gm.** | | | | | 1.7:1 * |
| *White* | 981 | 5 | 83 | 84.6 | |
| *Black* | 355 | 13 | 53 | 149.3 | |
| **Unknown** | | | | | |
| *White* | 8 | 0 | 2 | - | |
| *Black* | 0 | 0 | 0 | - | |
| **All Wt. Classes** | | | | | 4:1 * |
| *White* | 18,047 | 87 | 135 | 7.5 | |
| *Black* | 2,669 | 13 | 79 | 29.6 | |

Asterisks associated with the black:white risk ratios indicate significant differences between the races.

Prepared by : Onondaga County Health Department, Bureau of Surveillance and Statistics
Data source: New York State Bureau of Vital Statistics

Mr. McHugh. Thank you very much, Commissioner.

I think our next witness will be Susan Stone, who is the Director of the Prenatal Care Assistance Program at the Mary Imogene Bassett Hospital in Cooperstown.

Ms. Stone.

## STATEMENT OF SUSAN E. STONE, M.S., R.N., DIRECTOR, PRENATAL CARE ASSISTANCE PROGRAM, MARY IMOGENE BASSETT HOSPITAL, COOPERSTOWN, NY

Ms. Stone. I want to thank you for this opportunity to bring to your attention some of the unique problems of women in the rural areas of Upstate New York.

The Mary Imogene Bassett Hospital Prenatal Care Assistance Program draws clients from eight counties in Upstate New York. These are mostly rural counties, including Otsego, Delaware, Herkimer, Madison, Schoharie, Oneida, Montgomery, and Chenango. We have seven outreach clinics that provide prenatal care to low-risk clients. This unique health care delivery system has been recognized by the community to be an effective method of providing accessible health care. These clinics are staffed by certified nurse midwives and nurse practitioners. We currently have four certified nurse midwives on staff. These certified nurse midwives travel to the outreach clinics one day a week to provide care and they perform 99 percent of the low risk vaginal deliveries at Bassett Hospital.

The lack of prenatal care providers is of primary concern and remains a pervasive problem throughout our multi-county service area. Schoharie County is an example of this. This is an area of great concern since their only obstetrical provider relocated to Albany in July of 1990. Planned Parenthood of Schoharie County is able to provide limited ambulatory prenatal care services to low-risk women, but all high-risk clients must be referred to MIBH or Schenectady for services, and this entails a one hour drive for most clients. Currently, there are no delivery services available in Schoharie County.

Delaware County is another area of great concern. Delaware County covers an area equal in size to Rhode Island. There are currently only two prenatal care providers in Delaware County. One is our outreach prenatal care clinic located in Delhi, New York, and the other is a single obstetrician in the far northeast corner of the county. He is nearing retirement and the hospital is recruiting for that position.

Delaware Valley Hospital has already closed its obstetrical unit as of June, 1990. The lack of service providers, combined with the obstacles including rural geography, weather and lack of available public transportation for women makes it very difficult for women in Delaware County to access health care.

Chenango County currently has no PCAP provider, although Planned Parenthood of Broome-Chenango Counties, with the support of Chenango County Rural Health Network, is planning to implement a PCAP program in the near future if start up funding is available. Pregnant women in that county access comprehensive

PCAP services in all the surrounding counties, including MIBH through the central and satellite sites.

Statistics for the eight identified counties show high rates of low birth weight, late or no prenatal care, and teenage pregnancy. All of these figures are above the average for Upstate New York. There is a strong correlation between high percentages of women receiving early prenatal care and lower percentages of women having low birth weight and infant mortalities.

It has been noted that the adolescent population who enters care later has poorer outcomes than the general population. The combination of poverty, rural isolation, and lack of resources further contributes to the risk factors related to poor pregnancy outcomes. These same variables have also been noted to contribute to factors associated with maternal/infant substance abuse issues, smoking, alcohol, and other drugs.

The MIBH catchment area extends over a 100 mile radius. There is minimal public transportation in this region. Transportation is often cited by clients to be the major problem in accessing initial and continuous care. Although the Department of Social Service is required to provide transportation services under Medicaid, the reality is that there are often several local DSS policies which limits access and utilization of this service. Thus, clients cannot benefit by a service to which they are entitled to under PCAP.

Examples of these might be such as there must be no other car in the household, even if that car is being utilized by a partner to go to work and it is not available for the client to use to come to prenatal care appointments. Another example is a two-week prior request and notification in advance as to when a ride is needed. It is not always possible for women. Furthermore, there tends to be minimal local community resources to provide the transportation.

Another vital resource to a successful pregnancy care program is the certified nurse midwife. Certified nurse midwives have been proven to provide especially effective care in providing comprehensive pregnancy care to women and their families, especially those who are medically indigent.

Nurse midwifery services are consistently successful in affecting changes in both maternal and neonatal, birth outcomes. Their methods of health care delivery have improved the access to and utilization of health care and other community services. This allows for a broadened and more collaborative approach to the coordination of services.

Midwifery services in the MIBH system have proven to be effective in providing the full scope of services to this rural population, especially since the philosophy and standards for care are consistent with New York State's PCAP Program. The CNM program also benefits the hospital by providing cost effective health care services, in an ever increasing health care delivery budget. With common goals recognized and efforts refocused, it has encouraged the development of a more collaborative and collegial relationship between the physician and the CNM.

Before a certified nurse midwifery program can be successfully incorporated into a pre-existing health care delivery system for prenatal care, certain issues must be dealt with, including: the attitudes of all health care providers regarding nurse midwifery; understanding of the role and the functions of a CNM in the health care team; distribution of workload among the total health care team, including on call issues; appropriate reimbursement to the CNM for services rendered, and access to delivery privileges; defined responsibilities; continuing education; malpractice insurance; and probably one of the most important is publicity and community education about what a nurse midwife is and what she/he may provide.

There is a tremendous need in all of Upstate New York for nurses who are interested in pursuing CNM as a profession to have available, accessible, and affordable educational opportunities to pursue this career of choice. Currently, the number of nurses who are interested in and apply to the few available schools in New York and out of state exceed the number of available student slots. All too often, potential candidates choose not to pursue this needed career because of lack of financial resources, lack of qualified preceptors, family responsibilities, relocation demands, and the added stress this undertaking demands.

Some general recommendations to help resolve some of these issues to improve access and encourage enrollment in nurse midwifery are as follows.

The government needs to address funding, regulations, licensing and access issues.

State education and health departments must work together to address potential resources that can be used for recruitment and flexible educational opportunities.

State education and health departments must work together to address the educational requirements, minimum standards for practice, and regulations and policies governing nurse midwifery.

Government must negotiate with major insurance companies and ad hoc committees to deal with these issues should be convened at various levels. Members should represent the CNM, OB-GYN, Family Practice, R.N. and other allied health care professions, as well as include representatives from government, insurance companies and consumers.

I look forward to actively participating in the efforts to improve health care policy which will enable women and their families to access quality care in a timely, cost effective, and therapeutic manner which will meet their needs.

Thank you.

[Prepared statement of Susan E. Stone follows:]

## Prepared Statement of Susan E. Stone, M.S., R.N., PCAP Program Director, Mary Imogene Bassett Hospital, Cooperstown, NY

Thank you for this opportunity to bring to your attention some of the distinct problems of women living in the rural areas of Upstate New York, in particular, their attempts to access health care particularly during pregnancy.

The Mary Imogene Bassett Hospital Prenatal Care Assistance Program draws clients from eight counties in Upstate New York. These counties include Otsego, Delaware, Herkimer, Madison, Schoharie, Oneida, Montgomery, and Chenango. We have seven outreach clinics providing prenatal care to low risk clients. This unique health care delivery system has been recognized by the community and hospital administration and staff to be an effective method for providing accessible and "sensitive" health care. These clinics are staffed by Certified Nurse Midwives and Nurse Practitioners. We currently have four Certified Nurse Midwives on staff. These CNM's travel to the outreach clinics one day per week. They perform 99 percent of the low risk vaginal deliveries at Mary Imogene Bassett Hospital. Our 1989 statistics reveal increasing rates of teen pregnancy, as well as a high percentage women with late entry into prenatal care which results in high rates of low birth weight and infant mortality. Herkimer County has an overall infant mortality rate higher than New York City and has the highest infant mortality rates in New York State.

AFFILIATED WITH COLUMBIA UNIVERSITY

The lack of prenatal care providers is of primary concern and remains a pervasive problem throughout our multi-county service area. Schoharie County, currently unserved, is another area of great concern since their Obstetrical provider relocated to Albany in July, 1990. Planned Parenthood of Schoharie County is able to provide limited ambulatory prenatal care services to low risk pregnant women. All high risk clients must be referred to MIBH or Schenectady for service (each 45 minutes from Cobleskill). There are no delivery services available in Schoharie County at this time due to these circumstances. Consequently, the sole hospital will be forced to close the Obstetrical Unit.

Delaware County (which covers an area equal to the size of Rhode Island) currently has only two prenatal care providers. One is our Outreach Prenatal Clinic located in Delhi, New York and the other is a single obstetrician in the far Northeast corner of the county. He is nearing retirement and the hospital is recruiting for that position.

Delaware Valley Hospital has already closed its obstetrical unit as of June, 1990. The lack of service providers, combined with the obstacles including rural geography, weather, and lack of available public transportation and resources make it very difficult for women in Delaware County to access health care.

Chenango County currently has no PCAP provider, although Planned Parenthood of Broome-Chenango Counties, with the support of the Chenango County Rural Health Network, is planning to implement a PCAP Program in the near future, if start up funding becomes available. Pregnant women in that county access comprehensive PCAP services in all the surrounding counties, including via MIBH through the central and satellite sites.

Statistics for the eight identified counties show high rates of low birth weight, late or no prenatal care, and teenage pregnancy. All of these figures are above the averages for Upstate New York. There is a strong correlation between higher percentages of women receiving early prenatal care and lower percentages of women having low birth weight and infant mortalities. It has been noted that for the adolescent population who enters care later, this group has poorer outcomes than the general population. The combination of poverty, rural isolation, and lack of resources further contribute to the risk factors related to poor pregnancy outcomes. These same variables have also been noted to contribute to factors associated with maternal/infant substance abuse issues (smoking, alcohol, and other drugs).

The MIBH catchment area extends over a 100 mile radius. There is minimal public transportation in this region. Transportation is often cited by clients to be "the major problem" in accessing initial and continuous care. Although the Department of Social Services is required to provide transportation services under MA, the reality is that there are often several local DSS policies which limit access and utilization of this service. Thus, clients cannot benefit by a service to which they are entitled under PCAP. Examples are:

- There must be no other car in the household (even if that car is being used by the partner for work and therefore is unavailable to the client for transportation).
- A two-week prior request and notification in advance as to when a ride is needed is required.

Furthermore, there tend to be minimal local community resources to provide the transportation (ie. drivers, outreach workers, vehicles, or extended family members with the ability to provide this service).

Another vital resource to a successful pregnancy care program is the Certified Nurse Midwife. Certified Nurse Midwives have been proven to be especially effective in providing comprehensive pregnancy care to women and their families, especially those who are medically indigent. Nurse midwifery services are consistently successful in affecting changes in both maternal and birth outcomes. Their methods for health care delivery have improved the access to and utilization of health care and other community services. This allows for a broadened and more collaborative approach to the coordination of services. Midwifery services in the MIBH system has proven to be effective in providing the full scope of services to this rural population, especially since the philosophy and standards for care are consistent with New York State's PCAP Program. The CNM program also benefits the hospital by providing cost effective health care services, in an ever increasing health care delivery budget. With common goals recognized and efforts refocused, it has encouraged the development of a more collaborative and collegial relationship between the physician and the CNM.

Before a Certified Nurse Midwifery Program can be successfully incorporated into a pre-existing health care delivery system for prenatals, certain issues must be dealt with:

- attitudes of all health care providers regarding nurse midwifery
- understanding of the role and function of the CNM or the prenatal health care team
- distribution of workload among the total health care team, including "on call" issues
- appropriate reimbursement to the CNM for services rendered
- access to delivery privileges

- defined responsibilities (ie. - high risk situations, etc.) and established protocols for care and services
- continuing education
- malpractice insurance and issues
- publicity and community education about what nurse midwifery is and provides

There is a tremendous need in all of Upstate New York for nurses who are interested in pursuing CNM as a profession to have available, accessible, and affordable educational opportunities to pursue this career of choice. Currently, the number of nurses who are interested in and apply to the few available schools in New York and out of state exceed the number of available student slots. All too often, potential candidates choose not to pursue this needed career because of lack of financial resources, lack of qualified preceptors, family responsibilities, relocation demands, and the added stress (physical, emotional, and financial) this undertaking demands.

Some general recommendations to help resolve some of these issues to improve access and encourage enrollment in nurse midwifery are as follows:

- Government (federal/state) needs to address funding, regulations, licensing, and access issues.
- State education and health departments must work together to address potential resources that can be used for recruitment and flexible educational opportunities (scholarships, the development or addition of CNM curriculae to existing nursing programs, incentive programs to bring CNM's to an unserved/underserved area, etc.).
- State education and health departments must work together to address the educational requirements, minimum standards for practice, and regulations and policies governing nurse midwifery.
- Government (federal/state) must negotiate with major insurance companies to address malpractice insurance and concerns.

- AD HOC Committees to deal with these issues should be convened at various levels. Members should represent the CNM, OB-GYN, Family Practice, R.N., and other allied health care professions), as well as include representatives from government (education and health departments), insurance companies, and consumers.

I look forward to actively participating in the efforts to improve health care policy which will enable women and their families to access quality care in a timely, cost effective, and therapeutic manner which will meet their needs.

Submitted by:

Susan E. Stone

Susan E. Stone, MS, RN
PCAP Program Director
MARY IMOGENE BASSETT HOSPITAL
ONE ATWELL ROAD
COOPERSTOWN, NY 13326-1394
(607)547-3226

Mr. McHugh. Thank you very much, Ms. Stone.

Our next witness is Mary Cooper, who is the Associate Administrator of Family Planning Services with the Onondaga County Health Department here in Syracuse.

Ms. Cooper.

## STATEMENT OF MARY O. COOPER, ASSOCIATE ADMINISTRATOR, FAMILY PLANNING SERVICES, ONONDAGA COUNTY HEALTH DEPARTMENT, SYRACUSE, NY

Ms. Cooper. Good morning and thank you for providing me with the opportunity to talk about issues of access to health care as it relates to infant mortality and the relationship between family planning and reducing infant mortality, the need for federal involvement and the available and quality services impacted upon by the federal government, and finally, our work with the New York State Council on Food and Nutrition. I would like to provide a brief historical perspective on family planing in reviewing the problem of infant mortality because I believe we need to look at where we come from to adequately address where we are going.

Family Planning has been seen as having a critical role to play in the reduction of infant mortality in this country since 1941, when the Surgeon General of the Public Health Service determined that federal funds could be allocated for family planning programs in health areas. However, it was in the mid-1960s that a national goal was set to ensure the provision of adequate family planning services for those who wanted but could not afford them. And, of course, in 1970, Title X of the Public Health Service Act gave priority to furnishing family planning services through categorical programs serving low income families. A major priority in the program then and now was to establish, expand or improve family planning services in areas with high rates of maternal, perinatal and infant mortality.

In the early 1980s, our agency in this community, in an attempt to evaluate how well we were reaching the at risk women in our community, developed a series of maps looking at poverty, educational status, low birth weight and infant mortality. And these maps were developed on city census tracts because city census tracts gave us a more defined look at own population of patients.

Simultaneously, because of the population that we serve, we were having difficulty in obtaining needed referrals for our patients. The majority of our patients in family planning fall into the category of the working poor. Most of them are uninsured. It became quite obvious that it did not mean much to do a cancer test on a patient if that patient could not afford the needed follow up care if we found a problem.

At that point in time the federal poverty level was much higher than the Medicaid eligibility in New York State. For example, a family of four could be no higher than 65 percent of the poverty level to obtain Medicaid. And it did not mean much if the facility providing prenatal care or any other medical center was next door if you did not have the means for paying for the service.

With the increasing amount of time being spent by our staff attempting to work through referrals for our patients and our own data reflecting growing infant mortality in this the community, we began to alert the community. George Christie, our Program Administrator, and I began to use our maps of the community to talk about the issues of access and growing infant mortality rates on the local and the national level.

Our involvement in working with the county's public health nursing division to write the first prenatal care grant in Onondaga County, called Pregnancy CARE, in the mid 1980s came about because many of our patients among those were being made late for prenatal care. I think frequently when we look at data of later or no prenatal care, we assume that it is the patient and not perhaps the institution that cannot provide care quickly enough. Even after that program, I think both Pregnancy CARE and Family Planning both saw, in fact, that we could see the patient initially, but they would have to wait a long time before they could get into some of the hospital programs, and we began talking about, as other people have mentioned, the need was not only for early, but continuous prenatal care.

I am sure the committee has heard a great deal about uninsured people in this country. It is estimated there are 83,000 people uninsured in the Syracuse region which includes Oswego and Madison Counties. As we began discussing issues of access in our agency, we began to develop the concept that access had to have physical, psychological and financial dimensions. The definition of access becomes important because it is defined in many different ways. Very recently just speaking to a physician about access of poor males to the health care service, he felt that if a person was willing to wait long enough and the doctors in a particular setting flipped a coin, they could eventually be seen. So the definitions of access become very important.

Fifty percent of our patients currently carried in our in-house social services are people who need help in obtaining additional medical care, even with the changes in the Medicaid structure. Our agency has fought to retain a sliding fee scale that goes to zero. Even so we face real problems when referring patients from our program because they do not wish to go for services and receive bills that they cannot pay or be demeaned in the process of trying to obtain the services. Therefore, critical health needs frequently continue unresolved unless intervention occurs.

There is no question that New York State has, in recent years, provided major funds to fill the gaps for specific services which have suffered through federal cuts including family planning services, prenatal care and supports for Medicaid. However, it was unquestionably, the clear federal guidelines carefully crafted and forcefully monitored by the federal regional offices across this nation which changed the manner in which health care was delivered to poor people in this country.

In the 1970s, there could be no question about definitions of access: psychological, financial or physical. The quality of care, for a brief time was palpable and evaluated. Agencies, states and regions which received funds for federal programs quickly learned to deliver services by those standards or they did not continue to receive the funds. It was during this period that our mortality rates in all age groups in this country began to decline.

In the late '70s, along with the decline in dollars for health care, a new health care concept called marketing entered the health care field. It was designed to promote health care services to increase the number of middle class patients to be seen in federally funded programs. The concept, ideally, was to provide more funds to serve the "at risk" population.

I believe that the inevitable happened: poor people and the people in need were increasingly left out of care in these programs. To market means to sell, and you cannot sell services to people who do not have funds. Human service and health care delivery have increasingly attempted to emulate business practices in making money, indeed, are encouraged to do so. That the ultimate goal of business and health care is different does not seem to bother us.

I would like to quote from three Syracuse social scientists in this area who made a comment early in the discussion of this whole concept, Rubinstein, Mundy and Rubinstein. They said in the late 1970s, "There is an inherent contradiction between the purposes of human service delivery and the profit making goal of entrepreneurship. Each has its place in the institutional fabric of a democratic, capitalistic society but they are not in the same place. Attempts by one organization 'to have it both ways' leads inevitably to systemic conflict. The entrepreneur in human services must violate one or the other set of principles he purports to combine."

I am very pleased to see that in our attempts to ameliorate the devastating infant mortality rate in Syracuse, we are moving back to the community worker concept. In preparing this testimony I spoke to one of the state regional nurses and she told me that I should talk to some of the newly hired community workers. She told me the story about some of them being sent out to visit noncompliant clients, and they found that these so-called noncompliant women had already lost their babies.

I have great hopes in this community's new attempts to deal with the service delivery issues which impact on infant mortality. How successful we will be will be dependent, at least in part, on how well we hear what the community worker has to say and how quickly we adjust our programs to meet the needs of the so-called "noncompliant woman."

Transportation is a major issue in this community. In 1985, our agency coordinated the Syracuse site of the New York State Hunger Watch, a small hunger study run by Dr. Victor Sidel. We became involved in the Hunger Watch because our clinical workers began reporting, particularly on Fridays, that there were women in our Family Planning clinics who had no milk for their babies over the weekend. Family Planning and other agencies within the Health Department and other members of the community formed the Hunger Advisory Committee and worked with Cornell University graduate students to measure and examine children coming to the Well Child Clinics in this community.

The study took place in two sites: the Bronx and in Syracuse. As far as back as '85, the sentinel clinic for hunger in the New York State pilot project was here in Syracuse on Hawley Avenue. We have had a lot of indicators that we were in serious trouble with morbidity and mortality.

In looking for factors creating the problems in Syracuse, certainly lack of transportation plays a major role. Women with small children with limited funds and no transportation have trouble getting to markets. It should be noted that at that time, people used in the Syracuse study as "controls," also reported hunger even though their children may not have reflected the developmental problems associated with hunger. During the period of the study, the Hunger Advisory Committee in the Health Department found that the application process for food stamps, WIC, free lunch, etc., was separated and rigorous and was done in different places. We found the food stamps application was more complicated than an income tax form.

I would just like to briefly say that as a member of the New York State Council on Nutrition, one of our priority recommendations for 1990 includes that the New York State Department of Health should advocate on the federal level for universal access to WIC. As a member of the Accessibility Subcommittee of that body, I strongly recommend that access issues in the area of feeding programs be carefully scrutinized locally, on the state level and nationally.

Finally, infant mortality across this country and around the world is an indicator of the health of a whole people, the health of a nation. It is the signal which informs us of how well we are doing in caring for our population. It is also the bell-weather of our societal and cultural problems. It is no accident that our nation has set different goals for the 1990 health objectives regarding infant mortality for whites and non-white populations. This difference is played out in our community. It is obvious that the infant mortality problem that we face is focused in the inner city and the black and Hispanic community where people are less able to access consistent primary care which could alleviate many health problems.

I am very hopeful with our new attempts to deal with this issue will ameliorate the problem. Thank you.

[Prepared statement of Mary O. Cooper follows:]

## PREPARED STATEMENT OF MARY O. COOPER, ASSOCIATE ADMINISTRATOR, FAMILY PLANNING SERVICES, ONONDAGA COUNTY HEALTH DEPT., SYRACUSE, NY

Good morning and thank you for providing me with the opportunity to talk about issues of access to health care as it relates to infant mortality, the relationship between family planning and reducing infant mortality, the need for federal involvement to insure the availability and quality of services and, finally, our work with New York State Council on Food and Nutrition. I would like to provide a brief historical perspective on family planning in reviewing the problem of infant mortality in this community. I believe we need to look at where we come from to adequately address where we are going.

Family Planning has been seen as having a critical role to play in the reduction of infant mortality in this country since 1941 when the Surgeon General of the Public Health Service determined that federal funds allocated to local health programs could be used to finance family planning programs. However, it was in the mid-1960's that a national goal was set to insure the provision of adequate family planning services within the next five years to all those who wanted but could not afford them. It was, however, the Family Planning Services Amendment of 1969 to the Public Health Service Act and, finally, the authorization of Title X under the Public Health Service Act in 1970 which gave priority to furnishing family planning services through categorical programs serving low income families. A major priority in the program then and now was to establish, expand, and/or improve family planning services in areas with high rates of maternal, perinatal and infant mortality.

In the early 1980's our agency, in an attempt to evaluate how well we were reaching the "at risk" women in our community, developed a series of maps looking at poverty, educational status, low birth weight, and infant mortality. These maps were developed on city census tracts because census tract data could help us track our patients, and give a much more defined picture of where problems exist in a community. Simultaneously, because of the population that we serve, we were having difficulty in obtaining needed referrals for our patients. The majority of our patients in Family Planning in Onondaga County fall into the category of the "working poor", most of whom are uninsured. It became quite obvious that it did not mean much to do a cancer test on a patient if that patient could not afford the needed follow up care if we found a problem. At that point in time the federal poverty level was much higher than Medicaid eligibility in New York State. For example, a family of four could be no higher than 65% of the poverty level to obtain Medicaid. It did not mean much if the facility providing prenatal care or the medical center itself is next door to your house if you did not have the means of paying for the needed service.

With increasing amount of time being spent by staff attempting to work through referrals for patients and our own data reflecting growing infant mortality in this community, we began to alert the community. George Christie, our Program Administrator, and I began to use our maps of the community and to talk about the issues of access and of growing infant mortality rates on the local level and on the national level. Our involvement in working with the county's public health nursing division to write the first prenatal care grant in Onondaga County, called Pregnancy CARE, in the mid 1980's came about because many of our patients were among those waiting for prenatal care. The program provided the initial visit for a patient to attempt earlier access for women by facilitating their entry into existing prenatal programs. Even after that program was funded, both the Pregnancy CARE Program and the Family Planning Program continued to see patients for their initial visit but they frequently had long waits before their second appointment at the hospital. While there are a number of factors that might account for this delay, including a lack of clinicians available to work in these programs, the excessive delays became a real concern. We began to talk less about "early prenatal care" and more about "early and continuous prenatal care" as the real goal for our patients. However, the lack of insurance available to people in our services meant they suffered even more because all levels of care for them and their families was and is frequently out of reach.

I am sure that this committee has heard much about the uninsured in this country. It is estimated that there are 83,000 people uninsured in the Syracuse region which includes Oswego and Madison Counties. As we began discussing issues of access we developed the definition of access to care having physical, psychological and financial dimensions. The definition becomes important since access is defined in many different ways. (As recently as six weeks ago in discussing access to health care for men in our area, a physician told me that men could have access to care if they were willing to wait long enough and the doctors in a particular setting would flip coins to see who would see them.)

Fifty percent of our patients currently carried on our in-house social service are people who need help in obtaining additional medical care. Our agency has fought to retain a sliding scale that goes to zero. We face real problems when referring patients from our program because they do not wish to go for services receive bills that they cannot pay nor to be demeaned in the process of trying to obtain the services which then add to the stresses that they already have. Therefore, critical health needs frequently continue unresolved unless intervention occurs.

There is no question that New York State has, in recent years, provided major funds to fill the gaps for specific services which have suffered through federal cuts including family planning services, prenatal care services, and Medicaid. However, it was the clear federal guidelines carefully crafted and forcefully monitored by federal regional offices across this nation which changed the manner in which health care was delivered to poor people in this nation. In the 1970's there could be no question about definitions of access; psychological, financial or physical. The quality of care was palpable and evaluated. Agencies, states and regions which received funds for federal programs quickly learned to deliver services by those standards or they did not continue to receive funds. It was during this period that mortality rates in all age groups began to decline. In the late 1970's, along with the decline in dollars for health care, a new health care concept called "marketing" entered the health care field. It was designed to promote health care services to increase the number of middle class patients to be seen in federally funded programs. The concept was,ideally, to provide more funds to serve the at risk population. I believe the inevitable happened; poor people and people in need were increasingly left out of care in these programs. To market means to sell; you cannot sell services to people who do not have funds. Human service and health care delivery have increasingly attempted to emulate business practices in making money. That the ultimate goals of each is different does not seem to bother us. Rubinstein, Mundy and Rubinstein, three social scientists in Syracuse, stated it well at the beginning of the argument in the late 1970's, "There is an inherent contradiction between the purposes of human service delivery and the profit making goal of entrepreneurship. Each has its place in the institutional fabric of a democratic, capitalistic society but they are not in the same place. Attempts by one organization "to have it both ways" leads inevitably to systemic conflict. The entrepreneur in human services must violate one or the other set of principles he purports to combine."

I am pleased to see that in our attempts to ameliorate the devastating infant mortality rate in Syracuse we are moving back to the community worker concept. In preparing this testimony the state regional nurse told me that I should talk to some of the newly hired community workers. She told me the story about some of them being sent by one of the programs to visit non-compliant clients. She reported that the workers went out to find that the "non-compliant" women were women who had already lost their babies. Although I have great hopes in this community's new attempts to deal with the service delivery issues which impact on infant mortality, how successful they will be will be dependent, at least in part, on how well we hear what the community worker has to say, how quickly we adjust our programs to meet the needs of the so-called "non-compliant woman".

Transportation is a major issue in this community. In 1985 our agency coordinated the Syracuse site of the New York State Hunger Watch, a small pilot study done by Dr. Victor Sidel. We became involved in the New York State Hunger Watch study because our clinical workers began reporting, particularly on Fridays, that there were women in our Family Planning clinics who had no milk for their babies over the weekend. Family Planning and other agencies in the Health Department and other members of the community formed a Hunger Advisory Committee and worked with Cornell University graduate students to measure and examine children coming to the Well Child Clinics in this community. The study took place in two New York sites; in the Bronx and in Syracuse. The sentinel clinic for hunger in Syracuse was on the northeast (Hawley Avenue) area. In looking for factors creating the problem in Syracuse, lack of transportation played a major role. Women with small children and no funds have problems in getting to markets. It should be noted that at that time, people used in the study as "controls" also reported hunger even though their children may not have reflected the developmental problems associated with hunger. During the period of the study, the Hunger Advisory Committee in the Health Department, found the application process for food stamps "more complex than a tax form". We also noted that various food and food supplement programs; WIC, food stamps, free lunch program, and school lunch programs needed to have one application process in the community. Currently, the New York State Council on Food and Nutrition's priority recommendations for 1990 included that the New York State Department of Health should advocate on the federal level for universal access to WIC. As a member of the Accessibility Sub-committee of that body, I strongly recommend that access issues in the area of feeding programs be carefully scrutinized locally, on the state level and nationally. Finally, infant mortality across this country and around the world is an indicator of the health of a whole people, the health of a nation. It is the signal which informs us of how well we are doing in caring for our population. It is also the bell-weather of our societal and cultural problems. It is no accident that our nation set different goals for the 1990 health objectives regarding infant mortality for whites and non-white populations. This difference is played out in our own community. It is obvious that the infant mortality problem that we face is focused in the inner city and the black and Hispanic community where people are less able to access consistent primary care which could alleviate many health problems.

Respectfully
submitted
Mary O. Cooper
Associate
Administrator
Family
Planning

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Mr. **McHugh**. Thank you very much, Ms. Cooper.

Our final witness on this panel is Mr. Thomas Herbek, who is the Chief Executive Officer of the Family Health Network of Central New York, and is also Chairman of the Rural/Migrant Committee of the Community Healthcare Association of New York State.

We are delighted to have you here as well, Mr. Herbek. I have been very liberal in terms of the five minute rule because all of you have had very worthwhile statements to make and I have been hesitant to interrupt. But, unfortunately, we are now down to five minutes left of the panel's time, and we can stretch that a little bit because I am sure we want to ask one or two questions.

But Mr. Herbek, we invite you, and if you can keep it to five minutes, it would be helpful, but I do not want to make a bad rule for you, having let everyone else go on.

Mr. **Walsh**. Mr. Herbek, if you would just hold up for one moment.

There are seats across the front if anyone would like to come up. All across the front there are six or seven seats up here. So please come up and fill them. You will be more comfortable. Right here, especially on this side.

Mr. **McHugh**. Go right ahead.

## STATEMENT OF THOMAS HERBEK, CHIEF EXECUTIVE OFFICER, FAMILY HEALTH NETWORK OF CENTRAL NEW YORK, INC.; CHAIR, RURAL/MIGRANT COMMITTEE, COMMUNITY HEALTHCARE ASSOCIATION OF NEW YORK STATE, CORTLAND, NY

Mr. **Herbek**. Thank you, Mr. McHugh and Mr. Walsh. I appreciate the opportunity to be here. I would like to set this discussion in the context of some general areas that affect rural health as well as perinatal care.

Many people look at the rural countryside and they think that living and working here must be really wonderful, something like seven days a week of the Waltons. Unfortunately, those of us in rural areas have not done the job in getting the word out about our particular needs. Some of that is understandable. The *New York Times* has a slightly higher circulation than does the *Cincinnatus Pennysaver*. But some of it is also the clientele we serve in rural areas. They do not make the headlines. They are not "special populations," which has been a priority for both federal and state funds over the past several years.

Except for the migrants in some areas, they are primarily white, they generally have a place called home, they generally do not have AIDS, they generally do not use coke or crack, but still rely on old-fashioned beer and whiskey.

But skyrocketing health care personnel costs and an aging rural population, combined with increasing rural poverty, mean that many will not get quality health care and some will get no care at all.

Rural poverty levels have now surpassed urban levels in the U.S. and health care providers are moving out en masse. The U.S. national average is 164 M.D.s per hundred thousand population. In rural areas, it is 53 M.D.s per hundred thousand population, or less than one-third of the average.

While 25 percent of the U.S. population live in rural areas, only 12 percent of the M.D.s and only 18 percent of the nurses live there.

With regard to social and political decisions, when year after year, health policymakers and politicians make decisions based on the greatest good for the greatest number, it means that rural people always end up at the back of the line.

According to the New York State Task Force on Rural Health Strategies, rural areas have lower population densities, more elderly residents below federal poverty levels, lower median incomes, and more culturally homogeneous populations than urban areas. And in New York State, rural areas have half the number of primary care M.D.s per one hundred thousand people, one third the number of specialists, half the number of dentists, and one-third the number of social workers per hundred thousand people. And there are three million people in New York State living in areas with fewer than 150 persons per square mile. This means that New York State has the sixth largest rural population in the U.S.

Access is a real problem also. Often health care services are inadequate or unavailable, and access problems are compounded by physical boundaries—mountains, lakes—limited transportation, and extreme weather. Add to this the instability of rural hospitals and EMT services, and it gets worse.

The current rural health care labor shortage leads to a vicious cycle. Frustration and burnout occurs amongst those who serve rural areas, many of whom then leave the rural areas, putting additional burdens on those that remain, which discourages new health care workers from entering rural areas.

If a rural community health center or private physician closes down their practice, in many rural areas the people lose their only provider of health care services.

In central New York, where I live and work, in 1987, two-thirds of the rural service areas were classified as severely acutely underserved, and half are designated as health manpower shortage areas, with a population ratio of at least 3500 people to one physician.

Many communities rely on a single physician with limited backup and adequate OB care is not available in many rural areas in this state. Infant mortality in some rural pockets of New York State is higher than any metropolitan area. Neonatal deaths in rural St. Lawrence, Oswego, Schoharie and Chenango Counties, and post-neonatal deaths in Herkimer and Greene Counties are all in the highest quartile for New York State infant mortality by 1987 data. Eight rural counties ranked among the top ten counties in infant mortality in this state. And with regard to teen pregnancies, ten rural counties were among the top 16 counties in New York State in 1987.

The terrain is harsh and distances are tough for both providers and patients. In three of the counties that we serve, there is no public transportation of any kind. My physicians spend an hour to an hour and a half on the road every day between the hospital and the health centers.

The percentage of uninsured is also higher in rural areas than in urban areas in New York State. In all of central New York, one in five people is uninsured, many are unemployed, but many are underemployed.

There are several actions that need to be taken to improve this scenario:

First, we need a fund to enhance the salaries of rural health providers, and the National Health Service Corps needs to be expanded. Although third party reimbursement is based on an idea that labor costs are lower in rural areas, in actuality, the opposite is true. Because of the isolation, burnout and lack of support systems, we must be competitive with urban areas, and often must pay a premium in salary to attract physicians, dentists, physicians assistants and other professionals who are in demand, especially now that the National Health Service Corps is providing almost no new physicians.

Two, we need a malpractice pool to entice OBs and family practitioners who do OB to practice in rural areas. Our society, and New York State, in particular, must decide to help to assure that even rural families deserve quality health care.

In November 1989, we began a Public Health Service of 330 funded perinatal care program in our rural network of community health centers. At the end of the first six months, out of 245 pregnant patients, 51 were teenagers and three were under 15. Almost one-half of all patients were in their second or third trimester before seeking any prenatal care. And out of 117 deliveries during this period, five were under 2500 grams, and there were 16 fetal deaths or miscarriages and one neonatal death.

Third, rural community health centers and private providers need to have their Medicare and Medicaid rates adjusted upwards to reflect the recruitment and retention realities faced in rural areas, as well as the loss of efficiencies in rural practices. I have no hope of reaching the economies of scale of my urban colleagues' health centers. In the mid-1980s, urban centers averaged thirty to forty thousand visits, while rural centers averaged only eleven thousand visits per year.

Fourth, I believe that rural experience needs to be a mandatory part of any health care training in the U.S. Unless those who enter health care professions can experience rural practice firsthand, many, if not all, will never consider it as an option.

We need to expand rural preceptorships to M.D.s, P.A.s, nurse practitioners, dentists, hygienists, and others, and it must be a carefully planned requirement of all training programs in this country. And medical centers need to offer continuing education opportunities in rural areas for rural practitioners.

Fifth, school health clinics need to be established in many rural communities throughout the nation. Currently, we are the sole rural school-based health program funded by the New York State Department of Health. However, community acceptance has been outstanding. In the first year, we have enrolled over 80 percent of the students in our four school health centers, and last year provided over 11,000 patient visits with over 40 percent of those visits to teens. I believe, and we have shown, that school health clinics can be accepted in rural communities, and there is a dire need for them in many communities.

Thank you very much.

[Prepared statement of Thomas Herbek follows:]

## PREPARED STATEMENT OF THOMAS A. HERBEK, M.B.A., M.ED., CHIEF EXECUTIVE OFFICER, FAMILY HEALTH NETWORK OF CENTRAL NEW YORK, INC., CHAIR, RURAL/MIGRANT COMMITTEE, COMMUNITY HEALTHCARE ASSOCIATION OF NEW YORK STATE, CORTLAND, NY

- Many people look at the rural country side and think that living and working here must be really wonderful,
  - something like seven days a week of the Waltons.

- Unfortunately, those of us in rural areas have not done the job in getting the word out about our needs.

- Some of it is understandable.
  - The NY Times has a slightly higher circulation than does the Cincinnatus Pennysaver.

- But some of it is also the clientele we serve in the rural areas. They do not make headlines. They are not "special populations".
  - Except for migrants in some areas,
    - they are primarily white,
      - they generally have a place called home,
        - they generally do not have AIDS
          - they generally do not use coke or crack, but still rely on old fashioned beer & whiskey.

- But skyrocketing healthcare personnel costs and an aging rural population,
  - combined with increasing rural poverty, mean that many will not get quality healthcare,
    - and some will get no care at all.

- Rural poverty levels have now surpassed urban levels and healthcare providers are moving out.
  - The US National average is 164 MD's/100,000 people;
    - in rural areas it is 53 MD'S/100,000 people.
      - or less than one-third of the average.
  - While 25% of the US population live in rural areas, only 12% of the MD's, and 18% of nurses live there.

- With regard to social and political decisions, when year after year,
  - health policy makers and politicians make decisions based on "the greatest good for the greatest number",
  - it means that rural people always end up at the back of the line.

- According to the NY State Task Force on Rural Health Strategies:
  - Rural areas have lower population densities, more elderly residents below Federal poverty levels, lower median incomes, and more culturally homogeneous populations than urban areas.
  - And in NY State, rural areas have half the number of primary care MD's per 100,000 people.
    - one-third the number of specialists,
    - half the number of dentists,
    - and one-third the number of social workers per 100,000 people.
    - and there are three million people in NY State living in areas with fewer than 150 persons per square mile. This is the sixth largest rural population in the U.S.

- Access is a real problem -
  - Often healthcare services are inadequate or unavailable.
  - And access problems are compounded by physical boundaries - mountains or lakes - limited transportation, and extreme weather.

- Add to this the instability of rural hospitals and EMT services,
  - and it gets worse.

- The current rural healthcare labor shortage leads to a vicious cycle-
  - frustration and burnout occur amongst those who serve rural areas
    - many of whom then leave the rural areas-
      - putting additional burdens on those that remain,
        - which discourages new healthcare workers from entering rural areas.

- If a rural community health center or private physician closes down their practice, in many rural areas the people lose their only provider of healthcare services.

- In central NY where I live and work, in 1987 two thirds of the rural service areas were classified as severely acutely underserved.
  - and half are designated as Health Manpower Shortage Areas, with a population ratio of at least 3500:1 MD.
    - The median is over 5,000:1 MD with a range up to 11,000:1 MD in central New York's rural areas.

- Many communities rely on a single physician with limited backup-
  - and adedquate OB care is not available in many rural areas in this state.
    - Infant mortality in some rural pockets of NY State is higher than any metropolitan areas. Neonatal deaths in rural St. Lawrence, Oswego, Schoharie, and Chenango Counties, and postneonatal deaths in Herkimer and Greene Counties are all in the highest quartile for NY State infant mortality by 1987 data. Eight rural counties ranked among the top ten counties in infant mortality. With regard to teen pregnancies, ten rural counties were among the top sixteen counties in NY State in 1987.

- The terrain is harsh and distances tough - for both providers and patients.
  - In three of the counties we serve, there is no public transportation of any kind.
  - My physicians spend an hour to an hour & a half on the road every day between the hospital and the health centers.

- The percentage of uninsured is also higher in rural areas than in urban areas in NY State.
  - In all of central NY, one in five people is uninsured;
    - many are unemployed, but even more are underemployed.

There are several actions that need to be taken to improve this scenario:

1) We need a fund to enhance the salaries of rural health providers, and the National Health Service Corps needs to be expanded.

- Although third party reimbursement is based on an idea that labor costs are lower in rural areas.
- In actuality, the opposite is true.
- Because of the isolation, burnout, and lack of support systems, we must be competitive with urban areas,
  - and often must pay a premium in salary to attract MD's, dentists, physicians assistants and other professionals who are in demand, especially now that the National Health Service Corps is providing almost no new physicians.

2) We need a malpractice pool to entice OB's and family practitioners who do OB to practice in rural areas.

- Our society, and NY State in particular, must decide to help to assure that even rural families deserve quality OB care.

In November, 1989, we began a Public Health Service 330 funded perinatal care program in our rural network of community health centers. At the end of the first six months out of 245 pregnant patients, 51 were teenagers and 3 were under age 15. Almost one-half of all patients were in their second or third trimester before seeking any prenatal care. Out of 117 deliveries during this period, 5 were under 2500 grams (low birth weight) and there were 16 fetal deaths or miscarriages and one neonatal death.

3) Rural community healthcenters and private providers need to have their medicare and medicaid rates adjusted upwards to reflect the recruitment and retention realities faced in rural areas, as well as loss of efficiencies in rural practices.
- I have no hope of reaching the economies of scale of my urban colleagues' health centers.
- In the mid-80's urban centers averaged 30 to 40 thousand visits,
  - while rural centers averaged only 11,000 visits per year.

4) Rural experience needs to be a mandatory part of any healthcare training course in the U.S.
- Unless those who enter healthcare professions can experience rural practice firsthand, many will never consider it as an option.

- We need to expand rural preceptorships for MD's, PA's, nurse practitioners, dentists, hygienists, and others
  - and it must be a carefully planned requirement of all training programs in this country.
    - And medical centers need to offer continuing education opportunities in rural areas for rural practitioners.

5) School health clinics need to be established in many rural communities throughout the nation.
- Currently we are the sole rural school-based health program funded by the New York State Deptartment of Health.
- However, community acceptance has been outstanding.
- In one year, we have enrolled over 80% of the students in our four school health centers, and last year provided over 11,000 patient visits, with over 40% of those visits to teens.
- School health clinics can be accepted in rural areas and there is a dire need for them in many communities.

Mr. McHugh. Well, thank you all very much. We have used our one hour, but I would like to take just a couple extra minutes to give Mr. Walsh and me a chance to spur some comment.

In terms of our second panel, I think I will be tougher to try to limit it to five minutes, six minutes at most, so that we do have some time for questions and answers. And I would invite any of you on the first panel who can stay with us, to do so that you can participate in that question period.

Clearly, the key problem is inadequate and in some cases no prenatal care, and you have all outlined a series of causes of that problem, each one of which could take us into a significant discussion. One of them, clearly, was the unavailability for some people of insurance. And, Dr. Meyer, you indicated that New York has just passed, the legislature has just passed a program which will enhance Medicaid coverage for those with up to 185 percent of the poverty line, which is encouraging.

I gather that there are people who are not eligible for Medicaid, that is, over 185 percent of poverty, the working poor who are also uninsured, and we have a gap in that particular population.

To the extent possible, I would be interested in hearing from you and others in terms of how we might measure that. Is that a significant group of people who are not insured by private insurance because their employers do not have coverage for them, and they are not eligible for Medicaid even under the expanded basis? So, I would like a brief comment, if you would, on that uninsurability problem.

Secondly, on transportation, Ms. Stone, you mentioned that, and all of you mentioned that transportation is a significant barrier and that is especially true, I suppose, in rural areas, but even in urban areas it can be a problem. If a mother has other children and is in the late months of her pregnancy, even taking public transportation in the City of Syracuse might be a problem.

But I was interested in your comment that although the law requires department of social services to deal with transportation, in some cases local rules preclude it. And you mentioned one or two of those rules which strike me as silly. If there is a car in the family, even if it is being used by one of the parents for work, that disqualifies the mother from getting transportation.

What can be done about that and how pervasive is that problem in our local counties?

I suppose that is enough from me. If you would, any of you would like to comment on either of those two problems, and then I will ask Jim if he has a comment or a question to ask as well.

Dr. Meyer. The issue of uninsurability is certainly a difficult one, and I do not think we do have a good measure of it now. One of the things we have been struck with, with our expanded Medicaid program to 185 percent of poverty for prenatal care, is how many of the people who have chosen to participate actually would have qualified for Medicaid before, I mean prior to the expansion.

So, at the moment I would have to say we do not have good numbers. I think that our birth certificates over the coming year will be good evidence, at least in terms of prenatal care, as to how many women were not eligible for the expanded Medicaid because they were above that limit, but also were unable to access any other form of insurance. To date, we do not seem to be finding that as far as prenatal care goes.

The child health insurance programs that I referred to actually would enable families to buy in at a low premium whether they are uninsured or underinsured even if they are above 185 percent of poverty. Again, that has not been signed yet by the governor. They are trying to work out some details on it, and so I do not know yet what its status is, but that would serve children up to age 13.

Mr. **McHugh**. You did give the amounts that they would have to pay.

Dr. **Meyer**. Yes.

Mr. **McHugh**. But would you repeat those?

Dr. **Meyer**. Yes. What I said was that families would have to pay between $25 and $100 per year per child. Now, that is specifically for families who are under 185 percent of poverty. There will need to be decisions made as to what the amount to be paid would be for families who are underinsured and are above 185 percent of poverty. We do not have those numbers yet.

Mr. **McHugh**. And this coverage would be comprehensive?

Dr. **Meyer**. Comprehensive primary care. At the moment it would provide only for all ambulatory services needed. Discussions are ongoing as to whether it will pay for hospitalization as well.

Mr. **McHugh**. Thank you.

Ms. Stone, do you want to elaborate at all on that transportation problem?

Ms. **Stone**. Yes. I would like to comment on that. I think this is just one of the difficulties, it is a real example of the difficulties of accessing the Medicaid system for these people. I think maybe this is a defense mechanism by departments of social services for being told that they had to provide a service that maybe they do not have the facilities to even provide. Is this their way of limiting the number of rides that they are going to give?

My guess is that we are imposing regulations on departments of social services that maybe they cannot even afford to provide and we need to look at those things before we say that this is going to solve the whole problem for transportation: DSS will provide the rides. Well, can they provide the rides?

And if they can, then I deal with eight counties and each county has a different set of rules for how to access Medicaid. I believe that we need a standardized system across all the counties. For example, if a patient moves from county to county, she has to restart the whole application process over again. There is no transferring from county to county because every county has a different set of rules. That is my comment on that issue.

Mr. **McHugh**. Thank you very much.

Jim.

Mr. **Walsh**. Thank you, Matt.

I would like to thank all of you for taking the time from your busy schedules to come in today. But I think this is a very important hearing and it gives us the benefit of your knowledge and experience. All have very, very excellent testimony.

I would like to just note briefly for the record that we have a full hearing room today, elected and former elected officials, including our current County Executive, Mr. Pirro; the former president of the NAACP, Wayne Dunham; doctors, nurses, social workers, mothers and fathers. So I think it is a very good representative sample of our community.

Dr. Meyer, you noted that there has been a recent improvement in infant survival statistics in New York State. Could you tell us what you attribute that to?

Dr. **Meyer**. I would like to say that it is due to our increased accessibility of prenatal care. I am afraid it is really too early to interpret that and those data are also provisional. They are 1989 data, and sometimes we learn more about misfortune after the fact. So, I am uncertain.

But I do think that we are making a difference in terms of increased access to prenatal care and we know that our PCAP program over the past years of its existence has contributed to a reduction in low birth weight of those families served, despite the fact that many families came into prenatal care later than they often do under Medicaid. We attribute that to the fact that these women often did not know that they would be eligible for prenatal care services. So I think with the enhanced accessibility provided by Medicaid, meaning that every women who is financially eligible will be now be able to access the program, I think we may see even earlier entry into prenatal care and hopefully there will be more of an impact.

Mr. **Walsh**. Thank you.

Dr. Miller, Washington tends to divide resources among many different categorical programs. Would it be easier for you on the local level if the money came from one source with one set of eligibility guidelines or regulations.

Dr. **Miller**. Yes. [Laughter.]

Mr. **Walsh**. Thank you for your concise response. [Laughter.]

Thank you.

Ms. Cooper, thank you very much for your testimony. One of the things that the harder and longer you look at the data, the statistical data, the more you realize that infant mortality rates get better and worse for black babies and white babies at about the same rate, but the incidents of infant mortality among African American babies is much higher always.

What can we do specifically to address that problem, because I think that really is where the major problem lies?

Ms. **Cooper**. I think truly that nationally you have to set the same standard. I think we are one of the few Western developed countries that have people of color that sets one standard for whites and one standard for blacks. You set a tone.

Two, I think you have to look at the issues of poverty, the minimum wage, and access. They all go together. If you do not have an insurance system, a national health insurance system, then obviously people who are consistently unemployed, the last to be hired, the first to be fired will not get care. I would just like to say that in many cases the outreach workers that are being hired back now, were let go of in the early 80's. I know in one instance, of a person who was hired 20 years ago, did a beautiful job but was the first to be let go. She has been rehired on little more salary than she made

20 years ago. We have to look deeply at our commitments to end poverty in this country.

I mean, we have a commitment in some areas to maintaining people at certain levels, and I think we in the health field tend to blame the victim. So, that I think there has to be a meaningful look at access. But access, as someone else noted earlier, involves much more than just access to health care. I think we need to look at what happened during the 1980s in relationship to our views of where our money went, and what was important. You are looking at a total societal fabric, but access is very important.

And I would like to say something in relation to what the gentleman said about rural health care. We have a problem in this country with classes, and it is not just racism. It is class. I think that the way we view people who do not make it impacts our ability to provide care. I said at another hearing that we are the only developed country left that demands death for not making it. We think that we have to look at how we set our standards nationally in order to get a different kind of response on any local level.

Mr. **Walsh**. Thank you. Mr. Herbek, from the rural perspective, and I come into this from another committee also, the Agriculture Committee, and we are very much involved in that committee also in rural health. One of the things that I consistently heard in Washington is that we have got to expand the National Health Services Corps. And your statement that there are no new physicians coming into rural areas through that program, would you like to expand on that a little bit, on the National Health Services Corps?

Mr. **Herbek**. In our health centers——

Mr. **Walsh**. I am not sure if too many people even know it exists, to be honest.

Mr. **Herbek**. The National Health Service Corps is a program by which physicians have their medical school paid for by the federal government, and then owe a certain number of years of service afterwards, depending on the amount of loans that they receive. Generally, between two and four years of service they then owe, and they have to serve that in a designated manpower shortage area.

Since 1972, our organization has used National Health Service Corps physicians to provide primary care throughout the rural areas, and there are a number of sites that have used these positions, not only rural, but it has been equally a rural and urban program. But it has placed physicians in the hardest to place places, places that would not have health care without National Health Service Corps physicians.

Last year I know there were over 600 vacancies that went unfilled in community health centers across the nation, both rural and urban, where physicians who have finished their obligation left National Health Service Corps posts and were not replaced.

The other thing that has happened is that for many community health centers when funds are being stretched thin as it is and there are no real new funds available, they have had to, in some cases, add twenty to forty thousand dollars per physician to get new physicians and recruit them and retain the physicians they have after they go off their National Health Service Corps commitment.

Mr. **Walsh**. Do you think there is a diminution of commitment on the part of incoming doctors toward rural health, or do you think it's a matter that there are fewer physicians coming in, or what is it?

Mr. **Herbek**. I think it is a combination. I think it is partly that there are fewer primary care physicians being put out into the system for the number of vacancies. The figures I heard last year were that for every physician coming out of a residency program last year, they had 11 vacancies to look at. I am not sure how accurate that figure is, but I think that is the reality that most of the physicians felt. They had numerous opportunities.

I think the other problem with rural areas is that there are some specific problems attached to rural areas that you do not have in suburban practices. The other problem with a lot of rural areas is we do not have the insurance that many urban suburban people have. Less than one out of five of my patients are on Medicaid and more than two out of five of my patients are uninsured for primary care. That makes a real difference in your ability to provide a practice in a rural site unless you have some sort of underwriting such as we do from federal 330 funds. But those funds are not available for private practitioners, and those funds have not increased since 1980.

Mr. **Walsh**. Thank you very much.

Mr. **Herbek**. Thank you.

Mr. **McHugh**. Thank you very much, Jim.

And again, my thanks to all of you on the first panel. If you can stay, we would be delighted to have you here. If not, I understand and again thank you so much for your contribution.

Our second panel will please come forward now. We have a little over 40 minutes, which is a short time, and I am going to ask our individual panelists to try to keep it to five minutes. I will apply a uniform rule to everybody on the second panel, and I will tap this little gavel at the end of five minutes, and would ask if you could try to close within a minute or two after that.

Our second panel consists of: Cherylene Billue, and correct me if I have misstated the name. Miss Billue is a parent and a member of the Subcommittee on Infant Mortality for the National Association for the Advancement of Colored People here in Syracuse. Cynthia Olmstead is the Director of Nursing at the Syracuse Community Health Center here in Syracuse. Kathleen Murphy is the Executive Director of the Consortium for Children's Services, also here. Dr. Warren Grupe is Professor and Chairman of the Department of Pediatrics, the SUNY Health Science Center here in Syracuse.

We thank you all for being with us, and I would very much proceeding in the order in which I indicated. And again, if you could keep your statements to five minutes, it will give us a chance for some informal discussion which is also an important part of our program.

Ms. Billue.

## STATEMENT OF CHERYLENE BILLUE, PARENT AND MEMBER OF THE SUBCOMMITTEE ON INFANT MORTALITY, NATIONAL ASSOCIATION FOR THE ADVANCEMENT OF COLORED PEOPLE, SYRACUSE, NY

Ms. BILLUE. In Syracuse, the risk to black infants is nearly triple that of whites according to the Onondaga County Infant Mortality Action Plan. And according to Cheryl Smith, who authored a report for the *Herald Journal, Herald American,* in February 1989, following six months of research and writing, she stated that for every white baby who dies before age one, two black babies die.

Now in Onondaga County the emphasis is on infant mortality during pregnancy, not infant mortality as a whole, which leaves the mother of infants few, if any, viable resources. In addition to low birth weight and late care efforts, other factors compromise the infant mortality rate which have not been emphasized.

There are skull fractures resulting from child abuse, poisonings resulting from parents' lack of knowledge of simple safety procedures, drownings and electric injuries. And according to the American Red Cross and the American Heart Association, thousands of babies die every year due to choking, suffocation, breathing disorders and Sudden Infant Death Syndrome, much of which could be prevented if parents were taught infant-child CPR.

In Onondaga County, finding a doctor to treat a sick child may be beyond the capability of a poor mother, because so few doctors are willing to provide treatment for the amount that Medicaid pays. In 1987, for example, that was $16 per visit.

Babies of poor families are also at high risk because most of Onondaga County's private obstetricians refuse to care for pregnant women who are on Medicaid. As of July 2, only two private obstetrical groups accept Medicaid, two private groups contract with the PCAP program, Pre-natal Care and Assistance Program, and only three private obstetricians and one private family practice group have shown interest in the new PCAP program.

For the rest of the county, currently there is only one private pediatrician who accepts Medicaid, but that is in North Syracuse, and only for patients who live in that area. Of the dozen or so pediatricians whom we contacted, a few said that while they do accept Medicaid, they are currently at capacity and cannot say when they will be able to accept new patients. According to the *Herald-Journal* series of Cheryl Smith, some health professionals have suggested that some doctors do not want black people or poor people in their plush offices. Other doctors, already reeling from malpractice insurance rates, believe that the poor are more likely to sue, according to a national study.

Now, this limits health care for the poor and uninsured women to the Syracuse Community Health Center, the clinics at SUNY Health Science Center and St. Joseph's Hospital Clinics, as the only prenatal and newborn options available for such a large population. All three facilities have been so swamped that sometimes women who call for appointments early in their pregnancies were not seen until their second trimester, and many were subjected to long hours in the waiting rooms and discourteous and uncaring doctors. Many had small children that had to be in the examination room because the clinics do not have child care facilities for patients, and poor mothers cannot afford to pay baby sitters each time they have an appointment.

Following the loss of four children during pregnancy, and the near loss of two others because I did not know infant-child CPR, I became deeply involved with the problem of infant mortality, especially as it pertained to the child's first year of life. Since December of 1989, I have been deeply committed to finding solutions for this devastating problem, and I have come to the realization that there are not enough programs that address mortality during the child's first year of life.

Since that realization, I have tried to educate as many inner-city mothers as possible on all aspects on infant mortality, and I have tried to bring an infant and child CPR program with basic parenting education to as many communities as possible. With most of my help coming from the Syracuse Housing Authority, and the Onondaga County Health Department Emergency Medical Services Bureau, some small progress as been made, but much remains to be done.

In May of this year I learned of the NAACP's interest in research in the area of infant mortality, and subsequently I became affiliated with the subcommittee working on the issue. After many hours of studying records and reports from a variety of sources, the committee has developed a list of recommendations which it feels must be incorporated in any comprehensive program to reduce and eventually eliminate infant mortality in this community. They are as follows:

Require mandatory education and training for pregnant mothers in infant and child CPR, incorporated with a basic parenting and life skills program;

Make an infant and child CPR program available to all mothers in the community, on a sliding fee-ability to pay basis, if necessary;

Arrange and provide transportation for pregnant mothers on Medicaid who have more than one child under the age of three for whom at home care cannot be provided;

Provide child care in the home, where possible, or at a facility if necessary, so that mothers can meet with their physicians privately;

Discontinue the arbitrary practice of penalizing mothers by cutting off welfare and Medicaid for missed appointments, and investigate the reasons to determine if they are capricious or valid;

Increase Medicaid payments to the physicians to a rate more compatible with private insurers, and strongly encourage private physicians to accept Medicaid patients;

Institute a Federal Insurance Plan for working mothers with income below the poverty level, whose employers do not offer health insurance;

Establish community-based outreach health precincts staffed with appropriate service personnel, including a nurse, nutritionist, home economist, medical technician, outreach worker, to provide information, education and health-related services;

Notify all prenatal clinics that discourteous service and improper treatment of any patient will not be tolerated, and that any complaint of this nature will be thoroughly investigated by the appropriate government people.

Now, as I said before, I have been involved with this since, deeply involved since 1989. But my two children, one stopped breathing due to SIDS and one choked. I did not know infant and child CPR. I was on welfare. I could not afford to pay the $35 to pay for the course. And then I found out that a lot of other people had that problem, especially where I live in the inner city. We have a lot of people who do not have phones. We have a lot of people who have more than one infant, infants up to one year. I have taken people into my home. I have escorted them. I became a baby sitter for them so they could get to appointments. I have provided bus fare, when necessary. I have helped them get Medicaid cards. I have called their social workers, if they were cut off. I have called their doctors. I have even helped them report doctors who treated them nasty or, you know, just medically unethical. And it has got to stop, it really does.

If you would come to the inner city and see the pride that these people have when it comes to their children, you will see exactly what I mean. You have mothers who when a child has a burn, put butter on the burn. They do not know simple safety procedures. They are not being taught simple safety procedures.

When my daughter was born at St. Joseph's Hospital, before they let me leave the hospital I had to sign up to take a basic parenting class which taught me how to wrap up the baby so I would not suffocate her when it was too hot. They taught me also how to bathe the baby properly so that the head did not fall too far back and water didn't get down into her throat. They also taught me what to do in case of choking. They teach you, to not lay the baby down on the side and feed the bottle because that causes ear infection. It runs from the ear to the nose to the throat, which can get worse. They taught me a lot of things. They also made it mandatory that before I left I had to have a car seat, and things like that have to keep being instituted. It might have to be said over and over and over again. But I have two healthy children now, and I know infant and child CPR now, because I caused such a fuss with not having the money to learn it and it should be something that is readily available. If 500 non-rescue personnel can be authorized to have this course for free, adult CPR, then parents should have training too. We have the higher percentage of deaths.

Mr. McHugh. We are going to have to wrap up, I am afraid.

Ms. Billue. In 1987, we had 85 deaths in Onondaga County due to infants after being born, including Sudden Infant Death Syndrome, congenital abnormalities, certain conditions originating in the perinatal period, and upper respiratory infections, and then there were other causes of deaths. But that is a total of 85 children dying in 1987.

[Prepared statement of Cherylene Billue follows:]

## Prepared Statement of Cherylene Billue, Parent, Member, Subcommittee on Infant Mortality, National Association for the Advancement of Colored People, Suracuse, NY

### NAACP TESTIMONY ON INFANT MORTALITY

"INCOME AND COLOR TRANSLATE INTO DEATH AND DISEASE IN ONONDAGA COUNTY."

The Infant Mortality Rate, (IMR), is usually expressed as the number of infant deaths per thousand live births, and is the key indicator of community health because it measures the health of the most vulnerable segment of any population.

The IMR in Syracuse is higher than that of 27 cities of comparable size, and among Blacks the IMR is disturbingly high at 27.4 deaths per thousand live births during 1981-1987. Compared with 18 larger cities, including New York, Boston, Chicago and Detroit, Syracuse has the highest Infant Mortality Rate of them all! In Syracuse the risk to Black infants is nearly triple that of whites, according to Cheryl Imelda Smith, who researched and authored a report for the Herald-Journal/Herald-American on the subject of poverty and disease in Onondaga County in February 1989. Following six months of research she discovered that for every White baby who dies before age one, two Black babies die.

But the emphasis in Onondaga County is on infant mortality during pregnancy, not infant mortality as a whole, which leaves mothers of infants few if any viable resources. In addition to low birth weight and late efforts to access care, other factors that comprise the IMR which have not been emphasized are skull fractures resulting from child abuse, poisonings resulting from ignorance of simple safety procedures, drowning and electrical injuries. According to the American Red Cross and the American Heart Association, thousands of babies die every year from choking, suffocation, breathing disorders and Sudden Infant Death Syndrome, much of which could be prevented if parents were taught Child or Infant CPR.

According to the series of articles by Cheryl Smith, if you have a sick infant in Onondaga County, finding a doctor to treat the child may be beyond the capability of a poor mother, because so few doctors are willing to provide treatment for the amount that medicade pays. In 1987, for example, that was $16.00 per visit, whereas some private insurance companies paid anywhere from $30 to $60.00 for the same services.

Many babies of poor families are born ill because their mothers do not know the importance of proper care during pregnancy, or cannot afford it. Although New York's medicaid benefits are said to be among the most generous in the country, this system denies good health care along the lines of class and race according to Smith. Even with social factors filtered out, she states, a racial disparity remains in the infant mortality death toll in Onondaga County.

People are falling through the cracks. Poor working mothers whose incomes are below the poverty level, earn too much to qualify for medicade, but have jobs with no insurance coverage, and consequently cannot pay for the increasingly high costs of medical care. Thus they have few, if any, options. Babies of poor families are also at high risk of death because most of Onondaga County's private Obstetricians refuse to care for pregnant women who are on medicade.

As of July 2, only two private obstetrical groups accept medicade, and two private obstetricians contract with the PCAP

[*](Pre-natal Care and Assistance) Program. And only three private obstetricians and one private family practice group have shown any interest in the new PCAP Program.

As for the rest of the County, there is only one private pediatrician who accepts medicaid, but that is in North Syracuse, and only for patients who live in that area. Of the dozen or so pediatricians whom we contacted, a few said that while they do accept medicaid they are currently at capacity and cannot say when they will be able to accept new patients. According to the Herald-Journal series by Cheryl Smith, some health professionals have suggested that some doctors do not want Black people or poor people in their plush offices. Other doctors, already reeling from malpractice insurance rates, believe the poor are more likely to sue, according to a national study.

That limits the health care for poor uninsured women to the Syracuse Community Health Center, SUNY Health Science Center Clinic, and St. Joseph's Hospital Clinic, as the only pre-natal and newborn options available for such a large population. All three facilities have usually been so swamped that sometimes women who called for an appointment early in their pregnancies were not seen until their second trimester. And then many were subjected to long hours in waiting rooms and discourteous and uncaring doctors. Many had small children that had to be in the examination room because the clinics do not have child care facilities for patients, and poor mothers cannot afford baby sitters.

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[*] PCAP pays for pre-natal care, testing, post-partum and delivery fees for mothers who can't get medicade, and whose income is at or below 185% of the poverty level. The New PCAP also covers hospital labor and delivery fees, while the Onondaga County Department of Health provides outreach and education.

Following the loss of four children during pregnancy, and the near loss of two others because I did not know Infant or Child CPR, I became deeply involved with the problem of infant mortality, especially as it pertains to the child's first year of life. Since December of 1989 I have been deeply committed to finding solutions to this devastating problem, and have come to the realization that there are not enough programs that address mortality during the child's first year. Since that realization I have tried to educate as many inner city mothers as possible on all aspects of infant mortality, and have tried to bring Infant and Child CPR programs, and basic parenting education to as many communities as possible. With the help of the Syracuse Housing Authority, and the Onondaga County Health Department Emergency Medical Services Bureau, some small progress has been made, but so much remains to be done.

Indigent and working poor mothers require many services, some of which are available in the community, although many are not aware of it. In addition to health care, many require food, furniture, baby sitters, escorts to agencies, and even living quarters. I have tried to provide assistance in these areas to the best of my own limited resources, but the need exceeds the capabilities of any one person.

In May of this year I learned of the NAACP's interest and research into the area of infant mortality, and subsequently became affiliated with the subcommittee working on the issue.

After many hours of studying records and reports from a variety of sources, the committee has developed a list of recommendations which it feels must be incorporated in any comprehensive program to reduce and eventually eliminate infant mortality in this community. They are as follows:

- Require mandatory education and training for pregnant mothers in Infant and Child CPR, incorporated with a basic parenting and life skills program;
- Make an Infant and Child CPR program available to all mothers in the community, on a sliding fee-ability to pay basis if necessary;
- Arrange and provide transportation for pregnant mothers on Medicaid who have more than one child under the age of three for whom at home care cannot be provided;
- Provide child care in the home where possible, or at the facility if necessary, so that mothers can meet with their physicians privately;
- Discontinue the arbitrary practice of penalizing mothers by cutting off welfare and medicaid for missed appointments, and investigate the reasons to determine if they are capricious or valid;
- Increase Medicaid payments to physicians to a rate more compatible with private insurers, and strongly encourage private physicians to accept Medicaid patients;
- Institute a Federal Insurance Plan for working mothers with income below the poverty level, whose employers do not offer health insurance;
- Establish community-based Outreach Health Precincts staffed with appropriate service personnel, including a nurse, nutritionist, home economist, medical technician, outreach worker, etc., to provide information, education and health related services;
- Notify all pre-natal clinics that discourteous service and improper treatment of any patient will not be tolerated, and that any complaint of this nature will be thoroughly investigated, and appropriate action taken if warranted;

- Discontinue the inherent class and racial factors which inordinately contribute to the premature deaths of all the infants in our community;
- Review all Medicaid policies to determine what other improvements can be made to correct the flagrant imbalance in this system.

On behalf of the NAACP I would like to express our thanks and appreciation to Congressman James Walsh for his initiative in recognizing the serious magnitude of infant mortality in our community, and to Congressman George Miller, for his understanding and foresight in convening this first field hearing here in Syracuse where the Infant Mortality Rate is one of the highest in the nation, comparing unfavorably with many underdeveloped countries.

We are hopeful that through the continued leadership and commitment of these men and this committee, significant strides will be made to erradicate infant mortality within the not too distant future.

Thank you for allowing us to address you.

(Mrs) Cherylene Billue
Presenter

## SUMMARY OF COUNTY HEALTH DATA TABLE 1:

## 1987 RESIDENT INFANT DEATH LIST

## ONONDAGA COUNTY, NY

| CAUSE OF DEATH | NUMBER OF RESIDENT INFANT DEATHS IN 1987 |
|---|---|
| Sudden Infant Death Syndrome | 10 |
| Congenital Anomolies (includes Spina Bifida and others) | 19 |
| Certain Conditions Originating in the Perinatal Period (includes Birth Trauma and others) | 38 |
| Diseases of the Upper Respiratory Tract (includes Pneumonia, Bronchitis and Influenza) and Other Respiratory Problems After Birth Not Otherwise Specified (includes Apnea) | 7 |
| All Other Causes of Death | 11 |
| Total Infant Deaths, All Causes | 85 |

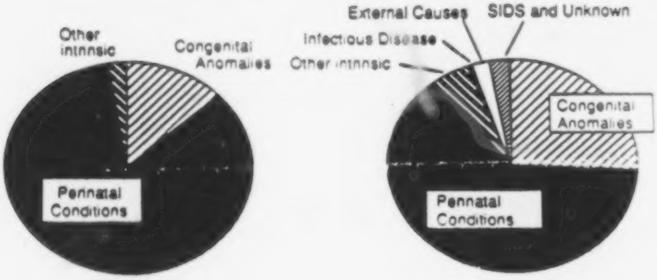
Source: New York State Department of Health, County Health Tables, 1987

Prepared By: Onondaga County Health Department, Bureau of Surveillance and Statistics

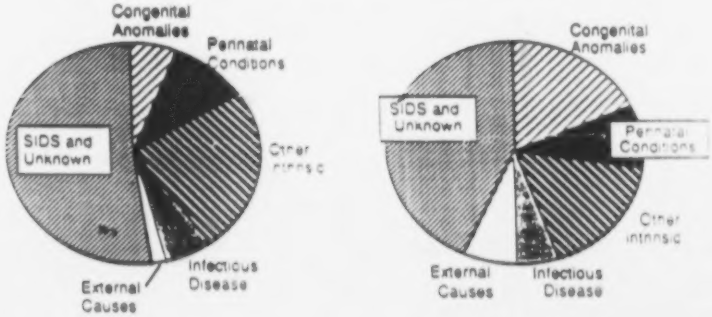
Appendix 1

## Causes of Infant Deaths Onondaga County Residents, 1981-1986

**Black Neonatal** **White Neonatal**



**Black Postneonatal** **White Postneonatal**



Prepared by Onondaga County Health Department
Bureau of Surveillance & Statistics

INFANT DEATHS DUE TO SIDS AND OTHER UNKNOWN CAUSES BY PERIOD OF INFANCY AND RACE
ONONDAGA COUNTY, NEW YORK, 1981-1987

| | RACE | |
|---|---|---|
| | White | Black |
| PERIOD | | |
| Neonatal | | |
| Number | 14 | 1 |
| Percent | 5.2% | 1.0% |
| Postneonatal | | |
| Number | 49 | 30 |
| Percent | 41.9% | 46.8% |

Percent = Percentage of Total Category-Specific Infant Deaths

Prepared by: Onondaga County Health Department, Bureau of Surveillance and Statistics
Data Source: New York State Health Department, Bureau of Vital Statistics

Mr. McHUGH. Thank you very much. Congratulations as well for taking some initiative on your own as an individual citizen to help other people in your community. I think it is a wonderful example for others who can make an impact just based upon their own initiative and idealism.

Our next witness is Cynthia Olmstead, who is the Director of Nursing at the Syracuse Community Health Center here in Syracuse.

Ms. Olmstead.

## STATEMENT OF CYNTHIA OLMSTEAD, DIRECTOR OF NURSING, SYRACUSE COMMUNITY HEALTH CENTER, INC., SYRACUSE, NY

Ms. OLMSTEAD. Thank you.

A heightened awareness and a sense of urgency has spread throughout the community of Syracuse and Onondaga County. Professional and lay persons are asking the question—Why is the infant mortality rate in our county so high? In trying to reply to this question one is inevitably forced to address, along with many other issues, the issue of access to health care.

My experience with this problem has primarily been through working with patients at the Syracuse Community Health Center for the last six years. The health center is located in downtown Syracuse and includes in its patient population a number of patients at high risk for infant mortality. While working as prenatal coordinator, women often share with me the difficulties they have with obtaining health care. I will share some of these difficulties, some of the ways we at Syracuse Community Health Center are responding to the problems and some barriers the center faces in providing care.

One of the most frequently heard problems has been transportation. A majority of our patients travel by bus. Even though we have a fine public transportation system, it becomes problematic to use when you are eight months pregnant, must walk to the bus stop in the rain or snow and have another small child walking with you or being carried by you. Through working with the CMCM program, it has become possible to offer patients more assistance with transportation, but we still have a ways to go.

Patients have also told me they cannot keep prenatal appointments because they have too many other appointments to go to. They may have to recertify for public assistance, pick up WIC coupons and meet with other social agencies. Needless to say, putting food on the table and having money to live with take a priority over keeping a prenatal appointment. The Center is working to provide as many of these services on site as possible. For example, doing presumptive eligibility and initiating WIC.

Language has also been a barrier to care. Syracuse has a growing Spanish-speaking community. Women will often come to appointments with a translator and the facilities have limited numbers of Spanish-speaking personnel to be of assistance. This results in a visit which can be frustrating for both the patient and the provider. Appointment keeping becomes very erratic because of such situations. I have to wonder also how many women may not be seeking care at all because they cannot even make a contact for their initial appointment due to a language barrier. While we continue to make efforts to recruit and maintain bilingual staff, resources are limited to support staff only to be available for translation.

Many patients who are late entrants to care have told me they were undecided about their pregnancy initially so they did not seek care. Their initial visit is often in their second trimester. We have intensified our educational programs in family planning in the importance of care.

The drug problem and domestic violence are also barriers to care which I have seen increase in the past years. Women using drugs often just don't have the ability to get into care, or are afraid to seek care because of the consequences they fear they will encounter. Unfortunately, there has been limited facilities to provide services for women on drugs. At the health center we do have a counseling program for substance abusers. Our program will meet with women right at the time of their visit and help arrange necessary services. However, if women need inpatient treatment, they have, at times, had to go long distances from home. There is a real need for more services for users of drugs, a heightened sensitivity for those on drugs and more preventive efforts.

With domestic violence, I have experienced women who were absolutely forbidden to receive care by their partners. Often they are too embarrassed to come in for their appointments because they are bruised. Again at the Center we do have a program to assist victims of domestic violence, but many women choose not to become involved. These women often have very sporadic medical care. Our facility hopes in the future to address the problem more fully by looking at increased treatment for the batterer.

One other barrier I need to mention is the ability of women to get an appointment into the health system. Women are constantly urged to make appointments as soon as possible, but then they have to wait three or four weeks for their first appointment. While there are several reasons for this delay occurring, I will mention two.

One is the need for more providers, both physicians and mid level. The second reason is the need to decrease the no show rate for appointments. A vicious circle has been created. People, due to barriers to care, miss appointments. Even with the overbooking of appointments, times are left vacant and appointments go unused. The Center works to resolve this problem by having persons do reminder calls and working to educate persons on the importance of continuous care.

Some barriers I have not mentioned are child care and fragmentation of medical care. The health center provides free child care. Also, since there are laboratory, pharmacy, sonography, and fetal monitoring services on site, women can receive their medical care in one place—the so-called "one stop shopping." This has really made an impact on more continuous care being received.

We have been able to arrange for WIC to be on site, but only for the patient's entry into the system. In the future we would like to see WIC coupons issued as a part of the prenatal visit.

Recently, we have also been working with the Department of Social Services on the CMCM program, Comprehensive Medicaid Case Management, and have taken the initiative to serve as lead agency for this program. The pilot project has placed a community worker in our health facility and others in the city. These persons go directly to the client's home to find out what the problem is with their accessing and continuing care. They then work with the patients to overcome barriers, and help them become more self-sufficient in the future. Their services might include arranging transportation, assisting with child care arrangements, or coordinating appointments. It is also offering the patient a defined person from the community who is saying I care about helping you get care and have the time to help you work through the barriers.

One thing I have found especially frustrating working with patients was the limit of time to deal with the non-medical issues. Also, I think a person going to someone's home will get a better assessment of what the needs might be.

Our Center has begun a mentoring program to match pregnant teens——

Mr. McHUGH. Ms. Olmstead, I am sorry to interrupt. I know you have a little bit more in your statement, but I do want to stop at this point, if I may, and we will come back. I know the mentoring program is one you were just getting to, and perhaps we can talk about that a little bit in the question and answer period.

Ms. OLMSTEAD. All right.

[Prepared statement of Cynthia Olmstead follows:]

## PREPARED STATEMENT OF CYNTHIA OLMSTEAD, DIRECTOR OF NURSING, SYRACUSE COMMUNITY HEALTH CENTER, INC., SYRACUSE, NY

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One of the most frequently heard problems has been transportation. A majority of our patients travel by bus. Even though we have a fine public transportation system, it becomes problematic to use when you are eight months pregnant, must walk to the bus stop in the rain or snow and have another small child walking with you or being carried by you. Through working with the CMCM program it has become possible to offer patients more assistance with transportation.

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Some of the barriers to care I have not mentioned are child care and fragmentation of medical care. The Syracuse Community Health Center provides free child care for its patients. Also, since there are laboratory, pharmacy, sonography, and fetal monitoring services on site, women can receive their medical care in one place - the so called "one stop shopping". This has really made an impact on more continuous care being received. We have been able to arrange for WIC to be on site, but only for the patient's entry into the system. In the future I would like to see WIC coupons issued as part of a prenatal visit. Recently we have also been working with the Department of Social Services on the CMCM program (Comprehensive Medicaid Case Management) and have taken the initiative to serve as lead agency for this program. This pilot project has placed a community worker in our health facility and others in the city. These persons go directly to the client's home to find out what the problem is with their accessing and continuing care. They then work with the patients to overcome barriers, and help them become more self sufficient in the future. Their services might include transporting the patient to their prenatal appointment, assisting with making child care arrangements, or coordinating appointments to make sure someone does not need to be in two places at one time. It is also offering the patient a defined person from the community who is saying I care about helping you get care and I have the time to help you work through the barrier that keeps you from getting care. One thing I have found especially frustrating in working with patients was the limit of time to deal with the non-medical issues. Also, I think a person going to someone's home will get a better assessment of what the needs might be. Our Health Center has also begun a mentoring program to match pregnant teens with women from the community. They will maintain contact through the last trimester of pregnancy and the first year of the baby's life, encouraging them to keep appointments and acting as role models. This program is also an attempt to be a bridging mechanism between prenatal and pediatric care. I believe there has been a lack of emphasis in this community on the importance of pediatric care. One can provide the best prenatal care, but if a person has no parenting skills or cannot bring their baby in for regular checkups, only half of the problem has been addressed.

In all, we offer a comprehensive quality health program and are constantly looking at ways to decrease the barriers to care, but as I mentioned we also have barriers to providing care. We have a program which was shown by a study in 1989 to have a low birth weight rate below other providers. However, our program can only be available to as many persons as our providers can see. We at the Center have a need for more physicians and mid-level providers. Secondly, there is a need for an increased realization that preventive programs and the staff to offer them are a necessity. Ideally women would enter pregnancies that are planned in the best possible health. It takes time and staff to educate persons to the importance of prenatal care, to the need for pediatric care, to ways to remain healthy between pregnancies. I can envision a program where waiting times for patients are used as education sessions rather than wasted time. Again the need for increased medical and preventive services. It is our goal to continue to provide our services to our patients and to develop additional means to improve our program to meet out patients needs.

In conclusion, I would like to say that I strongly believe our community will see this problem reverse. To do so we must continue to realize that infant mortality is not only a medical problem, but also a social one. The emphasis should include pediatric care and parenting. The community must listen to the patients. My concern is that as a community work together quickly enough with definitive action and most of all let us be creative and efficient but let us not duplicate efforts, lets build on programs that work. I am confident that our program at Syracuse Community Health Center has proven and will continue proving that it works. I am confident that our coordinated, patient oriented efforts a the Center and within this community will help to assure more babies survive.

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Mr. McHugh. Our next witness is Kathleen Murphy, who is the Executive Director of the Consortium for Children's Services.

## STATEMENT OF KATHLEEN MURPHY, EXECUTIVE DIRECTOR, CONSORTIUM FOR CHILDREN'S SERVICES, SYRACUSE, NY

Ms. Murphy. Thank you very much. I am very pleased to be here today to discuss the work that the consortium does in preventing infant mortality by enabling parents to fulfill their essential role in the healthy development of their children.

We believe very strongly that giving parents skills and resources to nurture their children is a key component in a comprehensive strategy to lower the infant mortality rate, particularly during the first year of life. The post-neonatal period, from one month to one year of life, is of special concern in Syracuse because the post-neonatal infant mortality rate is so much higher here than nationally or statewide, and it is rising. For African American teenagers in the City of Syracuse, the post-neonatal rate is now higher than the neonatal rate—a situation that is usually only seen in developing countries. That rate is often thought to reflect social conditions, care for children and the availability of medical care for treatable conditions such as infections.

During the first year of life strong parenting skills are essential to children's health. Parents need to know how to provide good nutrition and daily care for their babies. They need to know how important stimulation and involvement are. They need to be able to recognize serious illness and to get medical treatment. These are not skills all parents automatically have. Teenagers especially need help learning them.

For the past 12 years, the Consortium's Magic Wagon early childhood development teams have been visiting families on a weekly basis where children are at risk for foster care because they have been abused or neglected. These are extremely poor families with complex social problems. The typical family that we visit has three young children under five, and very often a baby is born during our involvement with the family.

Typically, the older children are already exhibiting a number of developmental and learning delays and serious behavior problems. They often have chronic health problems. Parents feel overwhelmed and unable to cope with their children's needs.

During our weekly visits, we provide stimulating learning activities for both the children and their parents. We provide toys and books. Our goals are to involve parents in their children's early learning, help parents understand how children grown and learn, and give parents skills for disciplining their children and coping with their behavior. Because we go so often and because parents get to know us well, we have a very strong relationship that is built with families and we become very much a support for the whole family.

However, on our first visits we often see babies who are left alone in their cribs for many hours. Diapers are not often changed, bottles are left propped—sometimes with sour milk, and the babies receive very little attention from their parents. They are not talked to very often, and sometimes they cry for long times without any response. With the home visitor's gentle persuasion, information, and support, the situation changes for these children, and we see some very dramatic turnarounds in families. Parents learn to cuddle, to talk, to play with their babies. The babies become more interesting, more alert, more curious and their health and their development improves, and that is the goal of what we are doing.

In the past few years it became very clear that we were too little and too late, that we needed to be visiting earlier in the life of the child and earlier in the development of the family. Most Magic Wagon mothers had their first child in their mid-teens and now are in their early 20s with two or three children. We felt that if we could visit earlier, we would make a greater impact on families and on the development of children.

And so three years ago, with the assistance of the state Adolescent Pregnancy Prevention Program and several foundation grants and some of our own resources, we began a new program focused on the needs of teenage parents, the Teen Parents and Babies Program. We currently have two teachers and two vans that visit 40 teen families each week, and that is probably less than 10 percent of the real need in Onondaga County.

Like the Magic Wagon, the Teen Parents Program provides stimulating activities for babies, helps young parents learn about child development and lends toys and baby equipment. A teacher begins visiting the teenage mother in late pregnancy to help her prepare for the birth of the baby and after the baby is born, and probably continues until the baby is about 18 months old.

Looking back over the past three years, the program has exceeded our greatest expectations. Nearly all the babies are developing normally, or doing better. Their mothers are closely attached to them, very aware of their needs, and providing good care.

We have not had the luxury of a formal evaluation system for the program, but we have informally reviewed each family's progress and each baby's development several times during the past two years. Based on our observations in the Magic Wagon program, we would expect these disadvantaged babies to be delayed in reaching normal developmental milestones, and we find that the opposite is true. The babies are developing on target and are healthy and bright.

In addition, the close relationship developed between program teachers and teenage mothers has enabled a number of the mothers to return to school or job training and take other important steps during self-sufficiency. I will just tell you about one of our families, basically because the child was at very high risk. He was born weighing less than three pounds to a teenage mother with two small children at home, was in neonatal intensive care in the first month and a half of his life, and we feel that our program was important support for that mother and that baby during his first year of life. A home visitor from our program was with the mother during labor. Because she had no one else to be with her. She helped arrange for a breast pump so that the baby could have breast milk during his stay in the hospital. When he went home, he went home to a crib that we had lent the mother. She had no funds for one of her own. We had helped her find clothing and blankets and donated them to her. His mother continued to nurse him, which is, we feel, an important and often overlooked piece of assistance for a low-birthweight baby. Program toys encouraged her to provide stimulation and early learning, and we just helped her cope with a tiny baby and two active toddlers.

Today, he is 14 months old. He survived his first year, and he is doing about as we would expect a normal year old baby to do. He is doing extremely well. His mom still has lots of problems, lots of social problems, lots of poverty problems, but she does provide good care for her baby and for her two children.

Mr. McHugh. Ms. Murphy, I am sorry to interrupt.

Ms. Murphy. Yes.

Mr. McHugh. But I would like to close on your statement if we may move on. But if you would like to make one last comment.

Ms. Murphy. Basically, I have some recommendations that I think are important. I think we want to see a firm funding stream for this kind of program coming out of the federal government, consistent funding, a consistent federal strategy for reducing infant mortality. We are also hoping that there will be expanded federal support for programs that reduce adolescent pregnancy and then the last recommendation is a very global one, but a very important one. That all parents have the financial resources that they need to provide their families with decent environments and adequate food, clothing and medical care.

Thank you.

[Prepared statement of Kathleen Murphy follows:]

## PREPARED STATEMENT OF KATHLEEN MURPHY, EXECUTIVE DIRECTOR, CONSORTIUM FOR CHILDREN'S SERVICES, SYRACUSE, NY

**Consortium for Childrens Services**
**Homebased Early Intervention Programs**
**Kathleen Murphy – Executive Director**

I am here to discuss the work of the Consortium for Children's Services in preventing infant mortality by enabling parents to fulfill their essential role in the healthy development of their children.

We believe that giving parents skills and resources to nurture their children is a key component in a comprehensive strategy to lower the infant mortality rate, particularly during the first year of life. The postneonatal period, from 1 month to 1 year, is of special concern in Syracuse because the postneonatal infant mortality rate is so much higher here than nationally or statewide and is rising. For African-American teenagers in the City of Syracuse, the postneonatal rate is now higher than the neonatal rate – a situation usually only seen in developing countries.

The postneonatal infant mortality rate is thought to reflect social conditions, care for children, and the availability of medical care for treatable conditions such as infections. During the first year of life strong parenting skills are critical to children's health. Parents need to know how to provide good nutrition and daily care for their babies. They need to know how important stimulation and involvement are. And they need to be able to recognize serious illness and to get medical treatment. These are not skills all parents have – teenagers, especially need help learning them.

As I am sure you will hear many times today, the infant mortality rate is much more than the reporting of deaths of babies, it is an indicator of the overall health and well-being of children in a community. For every baby who dies, there are many more who are developmentally delayed, others who will have health problems for the rest of their lives. So our goal is more than simply to prevent infant deaths, it is to improve the health of babies and young children and increase their chances for healthy, normal development.

For the past 12 years, the Consortium's Magic Wagon early childhood development teams have been visiting families every week where children are at risk for foster care placement because of abuse or neglect. These are extremely poor families with complex social problems. The typical family has three young children under 5. Very often a baby is born during our involvement with the family.

Typically the older children are already exhibiting a number of developmental delays and behavior problems. They frequently have chronic health problems. Parents are overwhelmed and feel unable to cope with their children's needs.

During our weekly visits, we provide stimulating, developmentally appropriate learning activities for both the children and their parents. We provide toys and books. Our goals are to involve parents in the children's early learning, help parents understand how children grow and learn, and give parents skills for disciplining their children and coping with their behavior. Because of the frequency and regularity of our visits and the relationship built with families, we are very much on-going support for the whole family.

On our first visits we often see babies who are left alone in their cribs for many hours. Diapers are changed infrequently, bottles are left propped – sometimes with sour milk. The babies receive little attention from their parents, are talked to infrequently, and let cry without any consistent response. With the home visitor's modeling, gentle persuasion, information, and support the situation changes for these children. Parents learn to cuddle, to talk, to play. The babies become more interesting, more alert, more curious. Health and development improve.

In the past few years, it became clear that our visits needed to begin much earlier – both in the life of the child and in the development of the family. Most Wagon mothers had had their first child in their mid-teens; with three children they are still in their early twenties. The Consortium felt that we could make a stronger impact on the healthy development of the children, if we began working with families before the birth of the first child to the teen mother.

Three years ago with the assistance of the New York State Adolescent Pregnancy Prevention and Services Program, several foundation grants, and our own funds we began a new program focused on the needs of teenage parents – the Teen Parents and Babies Program. We currently have two teachers and two vans that visit 40 teen families each week, about 10% of the estimated real need in Onondaga County.

Like the Magic Wagon, the Teen Parents Program provides stimulating activities for babies, helps young parents learn about child development, and lends toys and baby equipment. A teacher begins visiting the teenage mother in late pregnancy to help her prepare for the birth of the baby. After the baby is born, home visits continue until the child is 18 months old.

Looking back over the past three years, the program has exceeded our greatest expectations. Nearly all the babies are developing normally – or doing better than that. Their mothers are closely attached to them, very aware of their needs, and providing good care.

We have not had the luxury of a formal evaluation system for the program, but we have informally reviewed each family's progress and each baby's development several times during the past two years. Based on our observations in the Magic Wagon program, we would expect these disadvantaged babies to be delayed in reaching reach normal developmental milestones – and we find just the opposite is true. The babies are developing on target and are healthy and bright.

In addition, the close relationship developed between program teachers and teenage mothers has enabled a number of the mothers to return to school or job training and take other important steps toward self-sufficiency.

Perhaps the easiest way to understand how the program works is to hear something about some of the teens and babies we have visited:

> Steven weighed less than three pounds when he was born nearly two months too early. His mother Angela was 18; she already had two other children. She was living on her own without support from her family or the baby's father. She had had a difficult childhood herself. Her mother left the family when Angela was very young, her father was an alcoholic who abused her.
>
> A home visitor from the Teen Parents Program stayed with her during her labor and helped arrange for a breastpump so that tiny Steven could have the benefit of his mother's milk even in the intensive care nursery. The program van took Angela home from the hospital and provided transportation so she could visit and hold Steven in the hospital.
>
> When Steven went home, we lent his mother a crib for him and donated clothing and blankets. Angela continued to nurse him for several months. Program toys encouraged her to provide stimulation and early learning. We helped her cope with a tiny, premature baby and two active toddlers.
>
> Today Steven is fourteen months old. He survived his first year – a major achievement. He is healthy and has reached the developmental level of most normal 1 year olds. It has not been an easy year for Angela, but she has provided good care for Steven and managed with the two older children.

> We first began visiting Lisa and Cindy when Lisa was three months old. Cindy was a "throwaway" teen. She was living with Lisa in any friend's apartment where she could find room. She was not very closely attached to Lisa and often left her with anyone who would watch her so she could go out. She was often furious with Lisa for not "behaving", for crying or not eating fast enough or wetting her diapers.
>
> The home visitor worried that Lisa might fall or have an accident because the apartment was so cluttered and unsafe. At first Cindy didn't pay much attention to the hazards, but that changed as our visits continued. She also became more calm and patient as she learned that Lisa's behavior was normal and acceptable.
>
> Today, with the help and support provided by the Teen Parents Program, Cindy has her GED and is finishing a course in accounting. Lisa is bright, curious, and well-cared for; she has never been abused. Cindy has her own well-kept apartment and plans for the future for herself and her child.

Ours is not the only homebased early intervention program. There are a number of others across the country. Some utilize paraprofessionals visitors, some use public health nurses, some, like the Consortium, employ child development educators. Most report excellent results in helping parents to provide better care for their children.

We do not have the whole answer to preventing unnecessary infant deaths, but we feel we have part of the answer.

In closing, we would like to offer the following recommendations for federal action to deal with the problem of infant mortality.

Recommendations

1. A reliable and sufficient federal funding stream be established for homebased early intervention programs for all high risk babies during their first year of life that would enable their parents to receive regular home visits from child development specialists or other professionals.

   We suggest that the medicaid program might be one funding resource.

2. A comprehensive federal strategy for reducing infant mortality in the United States be adopted that includes: payment for early and ongoing prenatal care, supplemental nutrition for pregnant women and their babies, substance abuse programs for pregnant women and women with infants, guaranteed hospital payments for uninsured women, pediatric care for infants, and homebased early intervention for high risk babies.

3. Federal support for programs that reduce adolescent pregnancy and early childbearing be increased.

4. Adequate financial resources be provided nationwide for all parents to raise their children in decent environments with sufficient food, clothing, and medical care.

Mr. McHugh. Thank you very much.

Let me stress that all of your statements will be part of our record, and I am sure Jim and I have read them all in advance as well, and they are excellent statements I must say.

Dr. Warren Grupe is our final witness for this panel. As I mentioned earlier, he is a Professor and Chairman of the Department of Pediatrics at the SUNY Health Science Center.

Dr. Grupe.

## STATEMENT OF WARREN E. GRUPE, PROFESSOR AND CHAIRMAN, DEPARTMENT OF PEDIATRICS, SUNY HEALTH SCIENCE CENTER, SYRACUSE, NY

Dr. Grupe. Good morning. I really do appreciate you having this meeting. I have learned a lot, and I hope you have too.

I think the conclusion that can come from this exercise, however, is that it is not a good time to be a child; we have heard many reasons why this morning. Let me just touch on a few of these.

There is now a resurgence of preventable diseases, including measles, and whooping cough. This goes beyond the problem of infant mortality. We are witnessing a return of tuberculosis and rheumatic fever, which should be gone also. We are now seeing a whole new group of societal-based diseases that did not exist before: drugs, alcohol, AIDS, child abuse, and sexual abuse. I would point out that since 1987, when we initiated a sexual abuse clinic for children, the attendance at that clinic has doubled each year. That is frightening.

When we turn to the infant mortality problems, there is no evidence to support the concept that this mortality is caused by inadequate access to medical or health care as the sole cause. Although medical care is not perfect, there is also some evidence that underutilization of available care is also there. Therefore, as we focus on the supply of medical care, I think it is also important to focus on the demand as well. The value of active intervention, in the form of outreach, has also been presented this morning.

The causes of decreased or inappropriate demand are multifactorial, with many societal based. It is urgent that we support the study already underway through the Onondaga County Health Department to define the etiology, because unless we know the etiology, we will not be able to devise the programs that specifically address these issues.

If I may interject, Syracuse is a very appropriate place to undertake such studies. This is a very good, highly motivated community. The census tracts that are involved are very clearly defined. There has been a good deal of information obtained already. There is less population flux. It is easy to track this population. As Madison Avenue has known for years, results obtained in Central New York are applicable to the rest of the Nation.

Now, prevention clearly is an important part of postnatal health care. It is an important part of any medical care program. No hospital has ever prevented a single disease. From what you have heard this morning, what is needed does not involve high technology. They are not very costly.

One of the things I would like to point out is that community-based programs were here in Syracuse. They were discontinued in 1979, because of unfortunate bureaucratic interventions over a single issue. I really wonder if child health care would not be in better condition now in Syracuse had those discontinued programs been continued; you also heard about that earlier this morning.

I would love to see an expansion of the school-based programs. Increasing numbers of our modern mothers are still in school. We cannot only help them, but help their infants and their education all at once. Physical and developmental services that at least meet the American Academy of Pediatric requirements should be established. It is remarkable how much can be done by properly trained developmentalists that help parents do the things they need to do.

The concepts and precepts of primary care need to be expanded and enlarged. It is not just giving baby shots. There are social issues involved. It includes the concept of parenting, the notion of dependency, and the fostering of responsibility. Now, how low tech can you get?

We can also invest in the adults for the benefit of these children; we have also heard examples of that this morning. For example, the number of pediatricians in central New York are decreasing faster than we are replacing them. Soon we will have an insufficient number of them. You have also heard about the shortage of nurses, midwives, and public health people. Furthermore, we cannot run a medical school without its teachers; we are even beginning to lose some of them.

We need to consider the mother and the child as a combined unit. They are together before birth; they remain together after birth. We need to recognize that in our planning.

It is very appropriate to start preventive pediatric care during the prenatal period. We need to have programs, as you have heard from this panel, that address mentoring and the development of parenting skills. We are all primates; primates must learn how to parent. We are not sparrows; we do not do it innately. We must be taught, and we parent the way we were parented. Efforts toward improving parenting skills are very important and clearly successful.

Let me just talk briefly for a moment about the PRIDE program at our own institution; pride is one of the programs designed to provide parenting skills education. We help parents to develop appropriate expectations to do the things that we really need to do as parents. We help the mothers return to school. We train them in the use of community services. We are not unique, but it is one that works.

There are only three staff members involved. Even with such minimal staffing, it works. They provide services to about 85 mother/child units at a time. Over the last 3 years, they have served 225 families. The results are encouraging. Immunization rates are better when compared to a comparison population. Their abilities to keep appointments are better; their use of nonappropriate medical sources, such as the emergency room, has gone down. For the 1989 group, the number of missed appointments was 62 percent less; that is a significant difference. The number of children who received their first DPTs was three times higher than the comparison population. The number of children who had completed their immunizations was 36 percent higher than the comparison population.

Now, what are the implications of this? First of all, training in parenting skills is effective. More importantly it is effectively sought and effectively assimilated by the group. Their attendance is maintained. The parameters of health maintenance have improved. The cost of the health care has been reduced. Why? Because the inappropriate use of nonscheduled care has also been reduced.

Whatever barriers that existed, these parents have overcome them. It is a personalized tutorial that addresses the adult needs, the adult self-esteem, and the adult capability. It is continual and it is comprehensive. It changes parenting behavior with a minimal change in both number and over the cost of the staff required for regular well-baby care.

The personalized attention and skill acquisition was in fact, the incentive that brought these families back to get the immunizations and the care for their child. It should be possible, in the future, to start this program during the prenatal period.

We have had to alter admission to the program because we are now becoming overwhelmed. Nevertheless, we should expand the function and scope of such programs designed to increase the mother/infant bond and to improve services for that unit. We need to enlarge the population served. We need to use criteria that are not based exclusively on income, but incorporate this concept of dependency: what is it that that mother/child needs? We need to allow these programs to remain in operation long enough to see a change in behavior. We cannot repeat what was done in this community in 1979.

The funding should be based on the program offered, not just the medical services. That means we change the way we think about what primary care services really are.

Thank you.

[Prepared statement of Warren E. Grupe, M.D., follows:]

## PREPARED STATEMENT OF WARREN E. GRUPE, M.D., PROFESSOR AND CHAIRMAN, DEPARTMENT OF PEDIATRICS, SUNY HEALTH SCIENCE CENTER, SYRACUSE, NY

### HEALTH AND MEDICAL SERVICES FOR CHILDREN

Prepared for the House Select Committee on Children
Youth and Families
Syracuse, New York
July 16, 1990

A child should expect to receive several supports from his/her societal environment: Nurture, Health, Education, Shelter, Nutrition and Preparation for Adult Life.

The data indicate that our society has not performed well in these areas: Children are the fastest growing segment of the homeless; children form a major portion of those under-insured for medical care; the immunization rate now is worse thân it was a decade ago; most every single target set in the late 70's for education and preventive health care for children has been missed; we see a resurgence of preventable diseases that should be gone, such as measles and whooping cough; we are witnessing a return of tuberculosis and rheumatic fever; new society based diseases now afflict children, including AIDS, drugs, alcohol, child abuse and sexual abuse.

The focus of this hearing is that the infant mortality in some areas of Onondaga County exceeds 25/1000, equivalent to what we denounce for the third world. There is no evidence, at the moment, to support the concept that this mortality is caused by inadequate access to medical or health care. There is some evidence that there is under utilization of the care available, the causes of which are multifactorial, and related to societal-based problems.

What is currently needed is real data about the etiology of those infant deaths and better correlation to the societal issues involved. For example, data from other areas would implicate both family violence and substance abuse as important factors. Other efforts can then be more intelligently formulated to amend the problem. This might include: pregnancy prevention in teens, adequate substance abuse treatment programs provided in safe settings, more creative and positive use of foster care, changes in family court practices, expansion of individual case management with broadened perspectives and programs to enhance access to community services.

Although the emphasis on education, nurture, shelter, love and protection should not be diluted, the focus of my testimony will be in areas of health and medical care.

Pevention is the hallmark of all successful medical programs. To this end, new emphasis should be given to programs that prevent the growing segments of morbidity and mortality of infants and children. While we have reached new heights in the correction of complex diseases such as cancer and congenital abnormalities, we have fallen further behind in the simple precepts of primary care. The axiom is true: no hospital, no matter how well equipped or staffed, has ever prevented a single disease. Therefore, new and vigorous initiatives should be directed towards the preventive elements of pediatric services. These should include:

- Adequate Prenatal Care;
- Programs to insure complete immunization for the 25% of children currently denied;
- Community based programs that are designed to actively seek and reach out to those who need health services;
- Expansion of school-based programs;
- Physical and developmental services that meet American Academy of Pediatrics standards.

The precepts of primary care must be broadened to include societal issues, the concept of parenting, the notion of dependency, and the fostering of responsibility.

Not all expenditures should be limited to services solely for children. The concepts of primary care must be broadened to include societal issues, the concept of parenting, the nature of dependency and the fostering of responsibility.
Investment in appropriate adults can also benefit the child. Examples include:

- Incentives to increase the number and quality of child oriented professionals, including physicians, nurse practitioners, developmentalists, and health educators. To illustrate, at the moment in Central New York, the attrition of pediatricians is not being matched by those entering the practice of pediatrics. As another example, individuals with Master level degrees in Child Development cannot find employment.

- Parenting in the human is a learned skill. Thus, it becomes important to provide programs that teach parenting skills to those at high risk, through school curriculums, during the prenatal period and concurrent with the child's postnatal management. There should be incentives established for those parents who do advance their skills in child oriented care.

One example is the PRIDE (Parent Infant Development Program) Program initiated at our institution in 1987. This program, which receives no direct government or foundation support, offers enrollment to all new mothers, 18 years old and younger, whose infant has received care in the nursery by a faculty member of the Department of Pediatrics. In 3 years, only one of approximately 225 mothers has refused the opportunity. The program provides personalized tutelage in Parenting Skills, Age Appropriate Expectations, Basic Health and Medical Care, and Basic Child Care. The program also helps mothers plan their return to school and provides information about which community services are available to assist both mother and child. Personalized contact is maintained both in the Ambulatory Unit and the home. Although the groups meet monthly, staff are available for mothers' concerns between visits. The staff requirement is minimal; these staff provide both medical and parenting care and advice for the 85 families currently involved; almost 225 families have been served in the past 3 years.

Results to date are encouraging. The primary immunization rate is 89% for PRIDE infants compared to 72% for regular clinic users and approximately 75% for the country at large. Not only do PRIDE parents maintain a high attendance rate for scheduled care, they also have a more appropraite use of non-scheduled medical services, such as Emergency Rooms.

Several changes have taken place since the inception of the program. The age of eligibility has been reduced from 19 to 18 years, because the acceptance of the program has been so high. Even with this change, the program is still experiencing difficulties meeting the demand. The period of enrollment has been extended from 6 months to one year to accommodate the continued need of parents. Home visits were added in October, 1989.

The implications of this program's success are many. Most importantly, training in parenting skills are effectively sought and assimilated by the target population. Only one parent has refused the service, attendance is maintained, parameters of health maintenance have improved, and the non-scheduled use of the health care system is more appropriate. Whatever barriers to access exist in the comparison populations have been effectively removed by a personalized tutorial service that emphasizes growth in adult capability and self-esteem through a constancy of personnel and care. Finally, a change in parenting behavior can be demonstrated with minimal changes in staff number that provides services concurrent with the child's postnatal primary care. It seems reasonable that such services could be started sooner, during the prenatal period.

- Expand, not contract, the functions and scope of programs designed to support the parent-infant bond and improve more comprehensive services for the parent-child unit. Enlarge the population served. Establish criteria that are not based exclusively on income. Allow such programs to remain in operation for the several years it takes to demonstrate an effect on human behavior. Do not make funding dependent on the medical services provided, but rather on the program services available.

Although preventative programs are designed to reduce the need for medical services, and will eventually, they should not yet be substituted for existing secondary and tertiary medical care facilities. Hospital based programs for children have also suffered from deferred maintenance and restricted growth. As examples, in Central New York:

* In 1989, 15% of children requiring intensive medical care could not find space in the only Pediatric Intensive Care Unit in the region;
* The only cardiac catheterization treatment and diagnostic laboratory for children is outdated and inadequate; reimbursement levels do not allow the hospital to replace the unit;
* Extracorporial Membrane Oxygenation therapy has been shown to reduce both morbidity and mortality of prematurely born infants; although available in adjacent states, it is not available for the newly born of Central New York;
* Services for the diabetic child are embarrassing;
* The average daily census in the major regional neonatal intensive care unit is regularly above 100% occupancy;
* Hospital tertiary pediatric facilities are the oldest and the most outdated in the State.

In the areas of major importance in the treatment of non-preventable complex diseases, there has been a forced mediocrity in pediatric medicine, based mainly on inadequate financial support. Facilities must be upgraded to at least the level of contemporary adult services. Outdated equipment must be replaced. Reimbursement must at least match costs. Incentives must be initiated to entice needed qualified pediatric consultants to the region and to prevent those already here from leaving.

Finally, to ignore the needs of infants, children, those who raise them and those who provide professional services to them is to mortgage a future this society cannot tolerate, indenture an expectant labor force we cannot waste, and functionally impair our national abilities to retain a leadership role into the next century. We can ill afford to overlook that, "the level of civilization attained by any society will be determined by the attention it has paid to the welfare of its infants and children." We are already witnessing the signs of such neglect in our nation. We have a new window of opportunity to correct that.

Respectfully submitted,

Warren E. Grupe, M.D.
Professor and Chairman
Department of Pediatrics
SUNY Health Science Center
Syracuse, New York

July 5, 1990

Mr. **McHugh**. Thank you very much, Dr. Grupe.

Now, if there are panelists from the first panel still here, we would invite them to come up and participate in the few minutes we have left for questions.

On the questioning, we will reverse the order and I will ask Jim Walsh if he has any questions or comments he would like to begin with.

Mr. **Walsh**. Thank you very much, Matt.

It is, unfortunately, we have limited time. Congressman McHugh and the staff have to fetch a plane back to Washington. I have the pleasure of being able to linger until tomorrow morning, when I will return.

Let me see if I can keep my notes straight here. Mrs. Billue, I would like to thank you especially for absolutely taking what must have been a very, very difficult period in your life and turning it into a very positive thing for our community, yours and mine, and for your commitment to this serious problem.

If there was one thing that Government could do in regards to this problem and emphasizing and prioritizing our efforts and resources, funding, where would you like to see that go?

Ms. **Billue**. Basically, I would like to see it in the form of basic parenting skills and CPR. It does not cost that much. In fact, from Onondaga County all I was asking for in a written proposal was $870, and from another source, sending letters to private industry, $435. That would have certified 500 young mothers, young and poor mothers, in infant and child CPR. You see, those few minutes when infant and child CPR can be started are the extra minutes that that child has to survive. I would like to see it implemented in such a way that everybody all over the United States has the opportunity to have that tool to combat such things as breathing disorders in the first year of a child's life, because it clearly states in this report from the county that in 1987, we had 85 deaths after birth.

Mr. **Walsh**. This would be similar to the program that you went through after leaving St. Joseph's Hospital?

Ms. **Billue**. Yes.

Mr. **Walsh**. Thank you.

Kate Murphy, when we were at St. Joseph's this morning, Dr. Constantine—is that how you pronounce it?—explained one of the most tragic facts of this whole process. That is the drug abuse problem and its effect on the children. And one of the things he said they have noticed is that because of the loss of oxygen during the period the child was in the womb, the child actually develops a smaller brain and a smaller head, and it is a visible difference. And one of the things he noted was that these children respond very slowly to—I am not sure if discipline is the correct word, but in a situation where the child is say agitated or whatever, the response is not prompt to a parent.

I do not know if this is something that a program such as yours can get to. I do not know if that is a developmental thing that cannot be changed, or if it can be affected in a positive way by working with parents and at least explaining that to them, that this child is going to respond more slowly than others.

Is that something that you can——

Ms. **Murphy**. Sure. I think that that is important. I think that the first thing that is really critical is that the parent of the child has to be sober and straight, and you have to make sure that the parent has received some drug abuse treatment. We do very poorly in our program with parents who are still actively abusing drugs or abusing alcohol. And then you have to deal with the issue that you have a baby who has some developmental problems.

There has been some research done with cocaine babies that has shown that, indeed, an active, enriched early childhood or infant stimulation program can turn around some of those effects. With Fetal Alcohol Syndrome, where the baby has been affected by the mother's alcohol use, the turnaround is not as good, and the hope is not as great. It is really important to deal with the mother's use of drugs during pregnancy, early during pregnancy, and then you have to also realize that you have got two things happening. If you have a mother of a baby who is really more interested in the drug, and that is what addiction means, or interested in alcohol, you have a lot of times that she is not aware or available to that baby.

So, the first thing really is to treat the addiction. The second thing is, yes, we certainly can do things with babies who have developmental problems, to change things for them. The earlier the better.

Mr. **Walsh**. Thank you.

I have a thousand questions, but I am going to defer to Congressman McHugh because we are running out of time.

Mr. **McHugh**. Thank you very much, Jim, and again my thanks to all of you for being here. It is very frustrating for you, I suspect, and certainly for us not to have more time to really talk about these things in depth.

One of the really impressive parts of the testimony today was the outreach efforts that some of you are making, because this personalizes the attention that women in need get. And I am curious, how are these programs now funded?

Yes, okay.

Dr. **Grupe**. We fund ours on voluntary contributions of both time and money from the physicians in the Department of Pediatrics. It has no other source of funding.

Mr. **McHugh**. And you have three staffers?

Dr. **Grupe**. Yes. All supported by the voluntary contribution of our pediatricians.

Mr. **McHugh**. Ms. Murphy, how about your program?

Ms. **Murphy**. We have kind of a patchwork of funding. Some from the state government, some foundation funding, and a lot that is raised by volunteers of the Consortium through their memberships or other ways that we do fundraising; very, very tenuous thread of funding.

Mr. **McHugh**. How much does an outreach worker get paid?

Ms. **Murphy**. Our home visitors get paid anywhere from $15,000 to $17,000 a year.

Mr. **McHugh**. And that is for five days a week, full time?

Ms. **Murphy**. Five days a week working in probably the most difficult situation in the county. There is no question that they go into the most difficult homes, dangerous situations, and go there every day.

Mr. **McHugh**. We have a rather perverse situation in our society when we pay the people that do the most valuable work the least. Sometimes the people who provide the least contribution to society make the most money.

Dr. **Miller**. Congressman McHugh, the county-sponsored programs depend on both state and federal funds to support the outreach workers that we support. And one of the things that we observed in a visit at Hartford is that many of the women who enter outreach worker programs have educational opportunities afforded to them both on a part-time basis and subsidized basis. And all of the workers who have left the program in Hartford, Connecticut, have moved up. They have gone into social work training. They have gone on to nursing school and hoping the women who are working in our community have the same opportunities to advance into a better paying job.

Mr. **McHugh**. What federal funds, Dr. Miller, are used in your program?

Dr. **Miller**. The county relies on a number, but the Medicaid program is underwriting some of our workers, and then the Prenatal Care Program.

Mr. **McHugh**. Yes, Dr. Meyer.

Dr. **Meyer**. The state is contributing approximately $2 million to outreach workers around the state. One of the things that I think would be most helpful would be if Medicaid could pay a specific rate for an outreach visit. As you know, Medicaid currently pays rates for medical visits or for visits to a social worker. There is no rate that is payable for an outreach visit. It has to be incorporated in the general package of services, but I think a specific rate would be very helpful.

Mr. **McHugh**. Well, that gets me back to the really fundamental question that Jim asked at the beginning, which some of you have responded to, but let me give the rest of you an opportunity, if you wish, to emphasize the point. And that is, how can we at the federal level be most helpful in terms of the problems which you have all described eloquently. We clearly have the Medicaid program which has been expanded to some extent to help that outreach. We have the WIC program which is targeted at this population and which clearly pays off in terms of the pregnant women and children who are served, although we are still only reaching 50 to 60 percent of the eligibles for WIC, and we have still a long way to go. Those are two big programs. You have just mentioned one, and, Ms. Billue, you have mentioned one as well.

Are there other suggestions that you want to be sure that you have us hear before we leave?

Ms. **Cooper**. I think you have to address some of the issues dealing with physicians. I think the lack of people being trained to become physicians or nurse practitioners under the Public Health Service has meant that the costs have risen phenomenally. I say that having been personally involved. We receive fewer funds to support people going into medical school; fewer people go for medicine. We have to look at other kinds of people who are extending health care, such as the nurse midwife, and nurse practitioners. I think you really have to look at also the impact of cuts in programs such as ours (family planning) which had a major outreach focus. All those people who used to be in the community are now working only in clinics or are no longer employed. I have to write another grant to get outreach—I mean, these elements are no longer a part of Family Planning. The cuts in these programs over the years, as Dr. Grupe pointed out, most of the things that were in place in 1979, that were lowering our mortality rates, have been cut out, and I think many of them have to be put back if we are going to be able nationally to deal with some of our issues. I think also support for medical studies is important to look at, among other things.

Mr. McHugh. Yes, go ahead, Mr. Herbek.

Mr. Herbek. As I said earlier, I think the National Health Service Corps has got to be expanded for both urban and rural areas. It has made a significant contribution for many, many years, and it is at a point now where it is making almost no contribution, and that is a real shame.

The second thing is——

Mr. McHugh. Let me interrupt you quickly there. These doctors who serve from two to four years after medical school, when they are finished their service, are they not being replaced at this point, or is there any replacement of these doctors at all?

Mr. Herbek. There has been a replacement from other National Health Service Corps positions in the past. But last year, my understanding was, there were over 600 vacancies that were unfilled, which means that services are having to be cut in community health centers nationwide because of the vacancies in physicians. That does not count the vacancies in mid level providers which extend physician medical practices such as nurse practitioners and physician assistants.

There have to be more dollars put into that program because in the end it is costing more dollars to all of us, because we are having to hire physicians from the private sector, which is much more expensive, if we can get them, or we are having to use recruiting firms which is costing thirty to thirty-five thousand dollars a shot to get one physician with no guarantee. That is one program, I think, which has to be expanded.

I think the other one is the 330 funding for community health centers. It has got to be expanded. That program has not kept up with inflation since the early 1980s, and it is one of the cheapest ways to provide quality health care to underserved areas.

The third one is an expansion of school-based health clinics where you can provide services to people right on site, to the children right on site. Parents do not have to take off from work. The children can ride the school buses and be seen on site at the school in a much reduced cost to both the parent and to the society at large.

And I think the fourth thing is an increase in coverage for the working poor. Particularly in rural areas, there are a lot of people that do not qualify for Medicaid because they are working, but they also have no other health insurance.

Mr. McHugh. Yes, Dr. Grupe.

Dr. Grupe. I will be shot by my colleagues for suggesting this, but I think the Public Health Service program is super, but insufficient. I would love to see a plan that would encourage or require that all physicians spend a portion of their career providing what our civilian medical service needs are within this country.

Mr. **McHugh**. Yes.

Dr. **Miller**. I would just like to reference the material and child health and preventive services block grants since it is enabling a number of preventive programs and to address Mr. Walsh's earlier issue of allowing us to implement programs without extensive program requirements.

Mr. **McHugh**. Yes, Ms. Olmstead.

Ms. **Olmstead**. I just agree with Dr. Miller, the need for preventive funding. The one thing that was not mentioned today that I think is important is that if we could get women to enter pregnancy in the best health status possible, it would certainly make the job a little bit easier, and we need more programs that can address the prevention of problems prior to pregnancy.

Dr. **Meyer**. The point has been clearly made today by a number of people about the importance of the maternal/infant diad, and yet our insurance stream, our public insurance stream really does not attend to that well.

As Medicaid has gotten increasingly unbundled from public assistance, significant numbers of people who are above the poverty level are able to access Medicaid. I do not think we have adequately thought of it as real health insurance program. We require the same sort of recertification that families have to go through who are on public assistance, and I understand the need for fiscal control, but I am concerned if we do not create an entitlement to insurance for both the mother and child throughout the period of the child's infancy, we have lost a great deal of what we could obtain by that expanded Medicaid.

So, I would like to ask you if you would consider changing Medicaid regulations so that once a mother enrolls in Medicaid her infant is automatically eligible for Medicaid, at least through the first year of that child's life.

Ms. **Billue**. Excuse me.

Mr. **McHugh**. Yes.

Ms. **Billue**. Also, I think there needs to be more community-based outreach centers. In my area where I live at, we have SUNY Health Science Center and Syracuse Community Health Center. And like it has been mentioned, a lot of times when you call, you are put on a waiting list. If you are a current health center patient, you can be seen. But if you are a new patient, you have to go on the waiting list. There needs to be somewhere in the community that you can go to get a prenatal assessment, some time or something prenatal, vitamins, blood pressure, if you are having pain, some type of fetal monitoring or something that you can get in the community, that you do not have to find a baby sitter to walk six to ten blocks to upstate, or four to five blocks to Community Health Center.

Syracuse Housing Authority has been working with me very heartily in my efforts to reduce infant mortality. We call it TRIM, Tenants Reducing Infant Mortality. They have a youth center where they are willing to give you space to set up these clinics with a nutritionist or whatever you might need. A lot of high-risk mothers cannot always make it all the way up the hill to the perinatal center with three children under the age of three. So, there needs to be more community-based outreach centers in order to combat it, or you are just going to have an ongoing load of people who will not access medical care because they do not have transportation or whatever, other things they need to get there.

Mr. McHugh. Thank you very much. You have all made some very constructive suggestions. I would like to be able to say we are going to go back to Washington this week and make sure they are all there, but you have certain sensitized us to the nature of the problem in this community and in the state, and we certainly will go back even more committed to trying to do what we can to help.

Jim, do you have any last comment you would like to make?

Mr. Walsh. I would like to thank you, Matt, very much. I would like to thank you very much for coming and being here today and lending your ear and thoughts to this very serious problem. I would like to thank all the panelists for taking time to come in and enlighten us and give us some concrete proposals that we can take back to Washington and work at.

There are a number of bills that are out there that can be worked on and amended, changed, current structures that can be changed and amended that we can have input to. So, I thank you for that.

I would also like to thank my staff, in particular, Shelia Brown, a Syracusan, now a Washingtonian, who really put this hearing together. I am very proud of what Shelia accomplished and all the rest of the staff. I would like to thank Fred Walker from the GSA for providing us the room today, and to all of you who came to show your interest and concern and I hope you as well as I did learn a great deal today.

Mr. McHugh. And in closing, I would like to express my appreciation again to Jim and his staff. We are here, in part, because the committee is concerned about this nationally, and, in part, because Jim has impacted our committee with his view that there is a special concern and some special initiatives that have been taken here in Onondaga County.

This has been a good hearing, not only because of the witnesses who gave us such a positive contribution, but as Jim has said, there are a lot of people in the audience whom I suspect could add to our educational experience if only we had more time. But we do appreciate and take note of the fact that you are here. That obviously indicates your own personal concern as well.

Let me again thank all of you for being here. I do and the staff have to make a plane for Washington. And so we appreciate your participation and your patience, and the hearing is now adjourned.

[Whereupon, at 11:30 a.m., the select committee was adjourned.]

[Material submitted for inclusion in the record follows:]

OFFICE OF COMMUNITY SERVICES
AND
SYRACUSE COMMISSION FOR WOMEN
THOMAS G. YOUNG, MAYOR

TO: The House of Representatives
Select Committee on Children, Youth and Families

FROM: The Syracuse Commission for Women
Helen Marcum, Chairperson

DATE: July 16, 1990

RE: Field Hearing on Infant Mortality

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On April 20, 1988, the Health Task Force of the Syracuse Commission for Women convened the first meeting of what was to become a broad-based infant mortality coalition. In attendance were local health and human service providers, government officials and hospital administrators who met to discuss the issue of infant mortality and to exchange information on how to promote better pregnancy outcomes for women and children.

Over the following 18 months, the Infant Mortality Coalition evolved in order to:

a. Alert the public to the issue;
b. Provide a forum for the exchange of information and promote networking; and
c. Explore strategies to more effectively assist women who are at risk of poor pregnancy outcomes, and their children.

The most important contribution made by the Infant Mortality Coalition was to initiate communication among the service agencies for the purpose of providing coordination among the many providers who work with high-risk women.

In June, 1989, a team of Syracuse University graduate students, under the direction of the Syracuse Commission for Women, conducted an elite opinion survey of key individuals in health and human services agencies. The Infant Mortality Opinion Survey report, a copy of which is attached to this memo, is the result of nearly 100 face-to-face interviews conducted by the graduate students. Since the findings represented in the report were opinion-based, the

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interview group did not make specific policy recommendations. However, several barriers to care were identified by the group:

a. FINANCIAL; women cannot afford prenatal care.
b. EDUCATIONAL; women may lack knowledge of the importance of prenatal and postnatal care. This is particularly the case with pregnant and parenting teens.
c. PHYSICAL BARRIERS; including lack of transportation, inconvenient location of services, and lack of child care for other children.
d. INSTITUTIONAL BARRIERS; overbooking of clinics, lack of continuity of care, lack of coordination of services and lack of sensitivity on the part of providers.
e. PSYCHOLOGICAL; poor motivation, lack of social supports, and mistrust of health care providers.

Much has been stimulated in the community in part, by the leadership role of the Infant Mortality Coalition. We commend Onondaga County for the development of a comprehensive plan to deliver and track services to at-risk women.

Current efforts of the Syracuse Commission for Women include a public education campaign to be conducted with the Junior League of Syracuse in cooperation with Blue Cross/Blue Shield and Onondaga County. The Infant Mortality Public Education Committee will develop and implement a plan to bring health information to the at-risk population. We will pay particular attention to developing materials and strategies which are sensitive to the issues of race, ethnicity, language and educational level of the target populations.

In addition, we will continue to explore ways in which the Syracuse Commission for Women can assist in addressing other problems which have an effect on the health of women and children, especially those most at risk. Our mentoring program which links at-risk teens from Fowler and Henninger High Schools with successful role models has been highly regarded as a means to prevent teen pregnancy. An expansion of this program to include all high schools and middle schools would help make an impact on the infant mortality rate by preventing initial or repeat pregnancies among teens.

The solutions to the problem of infant mortality will not be easy to achieve but we will continue to contribute our expertise.

[Complete Infant Mortality Opinion Survey is retained in committee files.]

## EXECUTIVE SUMMARY

### PROBLEM

The infant mortality rate for Syracuse-Onondaga County is 17.8 deaths per 1000 births. This is significantly higher than the national average of 10 deaths per 1000 births. These deaths have been attributed to poor prenatal and postnatal care. This research project sought to draw out the perceptions of various professionals involved in the delivery of health care as to the causes of the high infant mortality rate, related available services, barriers to care, identification of high risk groups, the role of the physician, and recommendations. The following is a brief overview of the results of this research.

### FINDINGS

The identified causes of infant mortality were lack of prenatal care and poor nutrition. This often results in low birth weight babies which is a strong determinant of infant mortality. Other contributing factors were substance abuse, smoking, and inadequate postnatal care.

The professionals identified three high risk groups: teenagers, blacks, and substance abusers. This was attributed to the steady increase of teenage pregnancies and the lower socioeconomic level of black families.

Several barriers to care were identified by the interviewees and broken down into five categories: financial, educational, physical, institutional, and psychological. The reported financial barriers relate to the fact that women cannot afford prenatal care. Women who are insured may not even be covered for prenatal care, which is considered preventive care. The education barrier pertains to women who lack the knowledge of the importance of prenatal and postnatal care. This is particularly true of teenagers having babies. Physical barriers reported include lack of transportation, poor location of services, and lack of child care for other children. Institutional barriers mentioned were overbooking of clinics, lack of continuity of care, lack of coordination, and lack of sensitive gatekeepers and providers. Psychological barriers include lack of motivation, lack of social supports, and mistrust of health care providers.

When addressing Syracuse's high rate of infant mortality as compared to comparable cities, many professionals expressed disbelief in the compiling of the statistics. Many believed the statistics were skewed due to the definition of Syracuse and the fact that Syracuse is the center for treatment of high risk pregnant women. Other interviews cited high unemployment rates, political conservatism, and lack of program advertisement.

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When asked to address the issue of race in relation to infant mortality, interviewees' perceived differences in linguistic and cultural barriers, high fertility rates, genetic traits, lack of extended family and lower income as the causes of a higher black infant mortality rate.

The role of private physicians in treating Medicaid patients is believed to be constrained due to low and slow reimbursement rates, and overloading, rigid paperwork. Outside of bureaucratic problems, attributes of Medicaid patients themselves were identified, such as the tendency for missing appointments and not following treatment regimens, which increases the likelihood of complications.

The last issue identified was services for "the working poor", those who aren't eligible for Medicaid and cannot afford health insurance. The overwhelming response to this was to lower the eligibility requirements for Medicaid so more people would qualify. Others recommended a universal health insurance plan to be run on a sliding scale basis.

Interviewees also made many suggestions for improving the health care delivery system including a return to the community health concept; an after-hours private physician volunteer clinic; increased numbers of public health nurses; increased and earlier family and sex education; and a publicity campaign to target the most at-risk population.

## RECOMMENDATIONS

Since the findings presented in this report are opinion based, there is no factual basis for the interview group to make policy recommendations. However, one substantiated fact which did emerge through the interview process was the lack of knowledge on the part of service providers about all of the available pre- and post-natal services. Therefore, it is recommended that **information about all available prenatal and postnatal care programs be coordinated through a single person who would be responsible for keeping all city and county employees aware of additions or changes to existing programs.**

**March of Dimes**
**Birth Defects Foundation**
**North Central New York Chapter**

**Central Division**
7658 East Molloy Road
Suite 115
Syracuse New York 13211
Telephone 315 455 2451

**East Division**
Campus Plaza
629 French Road
New Hartford New York 13413
Telephone 315 724 5804

**North Division**
Public Square
547 Woolworth Building
Watertown New York 13601
Telephone 315 782 8580

**Angela R. Vigliotti**
Chapter Director

July 9, 1990

Honorable James T. Walsh, Congressman
1269 Federal Building
Syracuse, NY 13260

Dear Congressman Walsh:

On behalf of the volunteers and staff of the North Central New York Chapter of the March of Dimes Birth Defects Foundation, I wish to convey to you and members of the select committee the seriousness of the infant mortality problem in our Chapter area. We are so happy to have the field hearing "Ensuring Healthy Babies in Upstate New York: Pressing Problems, Promising Strategies" in Syracuse.

As can be seen by supporting documents, all counties but one in our nine county chapter area have an infant mortality rate well above the Surgeon General's goal of 9 per 1,000 live births. Indeed, in three counties the rate is almost double, based on 1987 figures. Within the city of Syracuse, the largest city in our Chapter area, that figure soars to 17.8% per thousand largely do to the horrendous rate of 30 per thousand amongst the black population in that city.

Within our Chapter, the March of Dimes supports our National initiative of the Campaign For Healthier Babies as a way of better attaining our goal to improve the health of America's babies by preventing birth defects and related conditions such as low birth weight. Through this Campaign, we are focusing our education, advocacy and community services efforts in each of our target areas based on direct needs within that area. Our intention is to assist those communities in reaching the Surgeon General's goals by:

1. Reducing the rate of infant mortality
2. Reducing the low birthweight rate
3. Increasing the rate of early entry into prenatal care.

We feel that March of Dimes is a leader in maternal and child health issues and will be even more effective in reaching our goals through the Campaign For Healthier Babies activities (see enclosures).

We can not, however, accomplish the task a hand alone. We must have the support and working partnership of all components of our society including corporate, government, education political, health care and pastoral segments. We need governmental support on both a statewide and national basis to see that families will be able to access early prenatal care. This can be accomplished by removing such barriers as financial (inadequate or no health insurance), lack of providers, lack of affordable transportion, and lack of adequate child care facilities. The growing issue of substance abuse must also be addressed, with more education programs becoming available, as well as a better means of indentifying at-risk babies and caring for them after birth.

We urge the committee's commitment and support of this problem.

Sincerely,

Philip Vennero

Philip Vennero, Chairman
Executive Committee
North Central New York Chapter

cc: George Miller
U.S. House of Representatives
Select Committee on Children, Youth and Families

PV/jp

[Materials from the Campaign For Healthier Babies is retained in committee files:]

## PREPARED STATEMENT OF JULIE A. FLACK, DIRECTOR, CHILDREN'S COMMUNITY SERVICES, BLUE CROSS AND BLUE SHIELD OF CENTRAL NEW YORK, SYRACUSE, NY

Since our founding over 50 years ago, Blue Cross and Blue Shield of Central New York has met the health care needs of its subscribers in our 10-county service area.

Even though the health care issues today are more complex and challenging than they were 50 years ago, our commitment to serve the health care needs of Central New Yorker's remains unchanged.

Like most members of the community, Blue Cross and Blue Shield of Central New York is very concerned about the alarming rate of infant mortality cases in Onondaga County and the city of Syracuse. Our concern over this serious community health problem has caused us to develop an infant mortality education/awareness program for pregnant women in Central New York. This program, called Caring for Tomorrow's Children, includes a series of public service announcements (PSAs) for television, radio, newspaper, transit and outdoor advertising mediums developed and produced by Blue Cross and Blue Shield of Central New York.

Our goal is to have all babies born healthy in Central New York. To this end, our role is to help organize the community to become involved in encouraging pregnant women to seek early and regular prenatal care.

Babies born with drug addictions and/or AIDS compound the challenges of our program. Blue Cross and Blue Shield of Central New York is devoting a large portion of our Caring for Tomorrow's Children program to education. We hope that, through education, women will be motivated to engage in healthy lifestyles during pregnancy. Our multi-media PSA campaign warns women about the dangers of using drugs, alcohol and not seeking early prenatal care. We plan to begin running these messages in Onondaga County by the end of July.

The Caring for Tomorrow's Children program exists because, as the old adage goes, "An ounce of prevention is worth a pound of cure." For example, it has been shown that an investment of as little as $500 in prenatal care can prevent a "problem birth" costing as much as $500,000 in high-tech neonatal unit services.

Every time a pregnant woman seeks out and receives prenatal care and gives birth to a healthy baby, medical costs have been averted. Healthy babies do not require expensive care in a hospital's neonatal unit. They also have a better chance of growing up to be productive members of the community than do their low birth weight counterparts, who begin their lives at a disadvantage. Adequate prenatal care and a healthy pregnancy can mean the difference for a child between a normal healthy life and a life filled with physical and mental burdens.

Blue Cross and Blue Shield's concerns for children is nothing new. Nationwide, Blue Cross and Blue Shield Plans provide prepaid health benefits to 21 million children. Locally, we have sponsored The Caring Program for Children Foundation which provides free primary and preventive outpatient health care coverage to eligible uninsured children in our 10-county service area. Recently, we celebrated the enrollment of the 1,000th child in the Caring Program, which began in April 1989.

Blue Cross and Blue Shield knows that it's Caring for Tomorrow's Children program is not the cure-all for the infant mortality problem. But, it is a start to help get the message to pregnant women to change their lifestyles and seek prenatal care.

**TIOGA COUNTY HEALTH DEPARTMENT**

231 Main Street • Owego, New York 13827 • (607)687-0623

Janet L. Bryant
Commissioner of Health

(607)565-9535

July 13, 1990

To: Congressman James Walsh

Subject: PCAP Educational Funding Requirements

The Tioga County Health Department has conducted its PCAP Program since July 1988; with client load approximately doubling each year. The burden of additional staffing is falling to the provider agency; in our case, a county health department already suffering reduced revenue.

The program in total and the number of clients has grown without funding provision for attendant staff growth and educational needs.

Please consider the following:

A. We have staffing requirements to meet adequate counseling and teaching needs for our rural high-risk population; who often have multiple psycho-social, economic, and educational limitations.

B. During the PCAP grant period, provision was made for staff salaries as well as for outreach and education positions. In our view, this educational funding has not kept pace with the client load and information needs.

C. A professional staff needs to keep current with technological changes related to high-risk pregnancy care. Constraints are imposed on professionals who must now pay for continuing education out of their own pockets without anticipated reimbursement for travel, materials, etc.

D. In 1989, grant dollars amounted to $500.00 for professional education expenses. In light of continuing demand placed on our agency, this is a small amount.

E. Tioga County's current starting salary of $19,165 for a BSN is the lowest in the 13 county Syracuse region.

While we continue to strive for quality care to our prenatal clients, for the above reasons, it is increasingly difficulty to provide adequate and comprehensive care.

Sincerely yours,

Marcia Glosick

Marcia E. Glosick
PCAP Program Administrator

/jt

COUNTY OF ONONDAGA

*Office of the County Executive*

JOHN H. MULROY CIVIC CENTER
SYRACUSE, NEW YORK 13202
315-425-3516
TELECOPIER 315-425-8582

NICHOLAS J. PIRRO
COUNTY EXECUTIVE

JAMES A. ALBANESE
ADMINISTRATOR PHYSICAL SERVICES

EDWARD KOCHIAN
DEPUTY COUNTY EXECUTIVE

KATHRYN H. RUSCITTO
ADMINISTRATOR HUMAN SERVICES

## Welcome and Comments to the House Select Committee on Children and Families

County Executive Nicholas J. Pirro
July 16, 1990

On behalf of the residents of Onondaga County I would like to welcome the distinguished members of the House Select Committee on Children and Families.

Two years ago this community made Children's Services a priority. We enhanced our child preventive and protective services, and began to look at our escalating infant mortality rates.

Today I am pleased to say we have put an action plan in place that is addressing these needs.

1) An Access to Care Team, headed by the County Administrator for Human Services, the Health and Social Services Commissioners meets weekly to monitor the plan's progress.

2) Fifteen community outreach workers are trained, and working in the field to ensure high risk women are getting the health and social supports they need. Some of these workers are stationed right in the clinic you visited this morning.

3) Special teams of public health nurses, social workers and outreach staff are available to take referrals and provide follow-up for all high risk pregnancies.

4) All maternal and child health care services are being carefully examined to enhance coordination. The Health Department is offering an integrated family clinic that includes a full range of services to women and children.

5) Onondaga County is designing an Access Center to provide computerized tracking of clients, entitlements and coordination of care. This Center will ensure that high risk pregnant women receive all the services that are necessary to conclude a healthy pregnancy. In addition the Center will track follow-up services for pediatric care.

In addition to these efforts a complete review is being made of every death of an infant to learn what other services may be needed.

Clearly as the level of government charged with providing human services, we must provide leadership in developing solutions on a local level. Even more importantly we need the broadest support possible to maintain these important services. We encourage the federal government to explore the current crisis in WIC and Medicaid programs.

Either we invest in early prenatal care or we risk the price of premature births, birth defects, low birth weights or infant deaths.

Onondaga County is proud of this community's efforts. We have much more do to and we thank the Committee, in particular Congressman James Walsh, for attention to the national problem of infant mortality.

**Cortland County**
**Health Department**
60 CENTRAL AVENUE
P. O. BOX 5590
CORTLAND, NEW YORK 13045-5590
TELEPHONE 607-753 - 5341

**JAMES V. FEUSS, P.E.**
*Director of Public Health*
ROBERT T. COREY, M.D.
*Deputy Commissioner*
*Medical Director*
V. NELLIE DIMON
*Secretary, Board of Health*

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Charles N. Poskanzer, Ph.D.
Mrs. S. Price, Legislator
Mrs. P. Wilson

July 13, 1990

FROM: Sarah A. Waller, Coordinator SAW
PHCP/PCAP

TO: HONORABLE JAMES WALSH

The Cortland County Prenatal Care Assistance Program serves approximately 40% of all women receiving prenatal care in Cortland County. Of these numbers, 30% are under the age of 21 years. Beginning 01/01/90 PCAP and Medicaid merged providing expanded services for eligible women. Unfortunately early and continuous prenatal care is now less accessable for the under 21 year old populace. These are barriers that we perceive.

1. There is a long time frame for determining Medicaid eligibility. Once pregnancy is established, the client is seen at PCAP usually within two weeks. The client may have to wait 2-4 weeks for a Medicaid interview. Documentation ie: landlord statements, household composition forms, etc. - is difficult to provide for the mobile client. After all the documents are provided, Medicaid approval takes a minimum of 30 days. Therefore, the pregnant teen may be seen at the Doctors office July 1 and the physician will not see the client again until she has a valid Medicaid card, which is not obtainable until September or October.

   The process is compounded by the fact our PCAP deals with 8 counties and each Department of Social Services varies as to for whom we may do a "presumptive eligibility".

2. If a pregnant woman under the age 21 applies for Medicaid, the Department of Social Services petitiions her parents to Court for support. This occurs whether or not she is married. The woman may elect to apply for the unborn only, however the unborn is not eligible for the expanded

Medicaid program.

3. Appellate courts vary from region to region. Our division requires the father of the baby (if not married to the mother before confinement) to reimburse to the county all medical costs associated with the pregnancy. In other divisions, i.e. Steuben County, only the nursery costs for the newborn must be reimbursed. A standard policy should be developed for the State. There should be no differentiation between the married and unmarried parents. Why not base eligibility strictly on income? We have seen a number of young people marry simply to avoid payback.
4. If a client has Medicaid coverage and applies for Public Assistance, her Medicaid stops. It is assumed the Public Assistance case worker will go back to the Medicaid expiration date, but this does not always occur and there is a break in coverage during which time prenatal services are provided and are not reimbursed.

IT WOULD BE OUR RECCOMMENDATION THAT:

1. Allow PCAP to do a presumtive eligibility on all pregnant women, regardless as to their age.
2. A Waiver to exempt all pregnant under 21 years old women from the parental support process.
3. Appellate Courts should be the same regarding paternity issues. Base reimbursement on income of the father and limit the charges to nursery costs.
4. Once a pregnant woman is determined eligible for Medicaid do not allow a lapse in coverage if she applies for Public Assistance.

**HEALTH SYSTEMS AGENCY**
**OF NORTHEASTERN NEW YORK, INC.**
PINE WEST PLAZA • WASHINGTON AVENUE EXTENSION
ALBANY, NEW YORK 12205 • TELEPHONE (518) 452-3300
FAX (518) 452-5943

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L 16 1990
Congressman Jim Walsh
Syracuse Office

July 16, 1990

Honorable James Walsh
1267 Federal Building
100 South Clinton Street
Syracuse, New York 13260-0188

Dear Congressman Walsh:

Thank you for the opportunity to offer testimony on issues relative to the delivery of prenatal and perinatal services in Northeastern New York State. As a health planning agency with grassroots input from 17 counties, the Health Systems Agency of Northeastern New York has identified several critical perinatal issues, and we are offering several suggestions for improvement in access to and availability of services. I hope the attached comments are useful to you in developing your legislative agenda.

Very truly yours,

Bruce R. Stanley
Executive Director

Enclosure

cc: Donna Cashman

711-1
D-2rh/90

ALBANY • CLINTON • COLUMBIA • DELAWARE • ESSEX • FRANKLIN • FULTON • GREENE • HAMILTON • MONTGOMERY
OTSEGO • RENSSELAER • SARATOGA • SCHENECTADY • SCHOHARIE • WARREN • WASHINGTON

## Prepared Statement of Bruce R. Stanley, Executive Director, Health Systems Agency of Northeastern, NY, Inc. Albany, NY

By the Health Systems Agency of Northeastern New York, Inc.

July 16, 1990

The Health Systems Agency of Northeastern New York is part of a statewide system of private not-for-profit health planning agencies established under New York State law. We are charged with the responsibility of planning for health services in a 17-county region, implementing health systems plans and reviewing applications for new and expanded health services.

Northeastern New York is a primarily rural 17-county region consisting of largely urban Albany County and 16 rural counties. Shortages in the availability of primary care services in general and perinatal services in particular in the region are evidenced by the designation of 25 federal Health Manpower Shortage Areas and 44 New York State Regents Shortage Areas within Northeastern New York.

The Health Systems Agency of Northeastern New York has employed several methods to identify and further define barriers to access to primary care and perinatal services. In 1986 the Agency developed The Northeastern New York Regional Plan for Primary and Preventive Health Care Service, which included a number of general and area specific recommendations for change. In 1989, the Subarea Advisory Councils of the Health Systems Agency of Northeastern New York sponsored four Rural Health Issues Forums in rural locations. A number of primary care and perinatal issues were identified and several solutions proposed. In addition, staff of the Health Systems Agency prepared, on a contract basis, eight Community Health Assessments for individual counties in satisfaction of the requirements of Article 6 New York State's of Public Health Law. A number of primary care and perinatal problems were identified and recommendations for solution set forth in these documents. Listed below are several issues identified through these processes and specific recommendations for addressing these concerns.

ISSUES:

1. Lack of availability of primary and perinatal care providers in rural areas.

   Private practice physicians are frequently reluctant to settle in rural areas where the population base is insufficient to generate an adequate income. In addition, reduced availability of peer support, continuing medical education opportunities for spouses further contribute to difficulty in recruiting and retaining family practitioners and obstetricians in rural areas. Further, low Medicaid rates for primary care providers coupled with proposed burdensome Medicaid cost containment measures and high malpractice rates restrict access to primary care by reducing the ability or willingness of some unregulated providers to care for patients. This is of particular concern in rural areas where primary care providers are already in short supply.

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Throughout Northeastern New York shortages of community health nurses, nurse midwives, nurse practitioners, physician assistants and other health professionals are reported.

2. Inadequate funding mechanisms for public health services.

   In undeveloped areas with low population density, population-based public health funding such as state Article 6 funding and local property tax-based funding of local health departments often result in underfunding of preventive health care servies to residents in greatest need. Scarce public health staff are often allocated toward services such as home health which have more secure sources of reimbursement.

3. Difficulty of networking in rural areas.

   In rural areas large geographic distances between communities and geographic barriers serve as additional obstacles to networking and coordination among health providers and limit efficient and effective use of scarce financial, personnel and administrative resources.

RECOMMENDATIONS:

1. Offer additional incentives for primary care and perinatal service provision in rural areas.

   *Structure loan forgiveness and other health personnel recruitment and retention incentives to allow mid-level practitioners such as nurse midwives, community health nurses, physician assistants and nurse practitioners to receive loan forgiveness and satisfy service obligations by locating in medically underserved areas.

   *Provide financial incentives to institutions of higher learning to establish residency/preceptor programs in rural areas.

   *Enrich Medicaid reimbursement for practitioners located in underserved areas.

2. Improve funding mechanism for public health services in sparsely populated rural areas.

   *Make available supplemental funding to low population density countries with poor health status indicators to establish or expand public health services.

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*Continue initiatives to coordinate health education and illness prevention activities of school districts, county health units and volunteer health and health education organizations. Support demonstration efforts to provide public health services in schools and conduct evaluations of model programs with results disseminated widely.

3. Support local level efforts at rural networking intended to overcome barriers to the devlopment of a full continuum of services caused by low population density and large geographic distances between providers.

*Provide financial incentives for planning and implementation of rural health partnerships with consideration given to consortia of two or more providers proposing to develop perinatal services in underserved areas. Evaluate demonstration projects and disseminate results to all health care providers and interested community organizations.

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D-2rh/90

## PREPARED STATEMENT OF KATHYLENE SISKA, M.S.W., RESEARCH SPECIALIST SUNY HEALTH SCIENCE CENTER, CLINICAL CAMPUS, BINGHAMTON, NY

My name is Kathylene Siska. I am a research specialist with Family Medicine, SUNY-Health Science Center, Clinical Campus, located in Binghamton, New York. I would like to thank the committee for their concern about the high infant mortality rates experienced in Upstate New York.

The South Central region of upstate New York has experienced infant mortality rates ranging up to 18.8 for a six county area during the period 1986 to 1988. There are many reasons for this high rate of infant mortality. I would like to address the lack of service providers for prenatal and pediatric care in this largely rural area and recommend that the federal government offer:

(1) tuition assistance for medical students who choose primary care specialties (Family Practice, Pediatrics and Internal Medicine).

(2) a permanent commitment to fund initiatives such as the Rural Medical Education Program.

(3) incentives to schools of nursing to provide midwifery programs.

The South Central region of upstate New York is underserved by practically every type of health care professional. There are not enough available physicians, nurses, dentists and other health care professionals to provide care to the largely rural population.

More than a half million people live in the upstate counties of Broome, Chenango, Cortland, Delaware, Tioga and Tompkins counties. Approximately 20-25% of that population base lives in close proximity to an urban area (Binghamton). The rest of the population lives in small towns and rural areas which are 1/2 hour to 2 1/2 hours from Binghamton or Syracuse.

These counties are geographically large. Delaware County alone is the size of Rhode Island. Although these areas might not qualify as underserved areas, health care services are concentrated around Binghamton and Ithaca. The rural population has limited access to the health care services, especially the prenatal and well-baby visits which can reduce infant mortality.

Although the infant mortality rates in these counties is less than the current rate in Onondaga County and Syracuse, the problem is more pervasive as the South Central area does not have easily identified "pockets" of high rates. This means that targeted programs will not significantly change the infant mortality rates for this area.

The high rates in Onondaga County may be reflective of poverty, lack of insurance or inability to access providers; the high infant mortality rate in the South Central area of New York adds the problem of a lack of providers in rural areas. Even a program of universal coverage for prenatal care and care for the first two years of a child's life will not impact this rural area due to the difficulties of getting to providers. If a woman lives in the northern regions of Tompkins or Delaware County, that woman has to travel an average of 1 1/2 to 2 hours one way to get to a provider.

More needs to be done to entice health care providers to locate in these rural areas. This can be accomplished by offering tuition assistance to medical students who enter primary care residencies (Family Practice, Pediatrics and Internal Medicine) and by expanding financing of initiatives such as the Rural Medicine Education Program developed by SUNY-Health Science Center to place medical students in rural areas.

It is estimated by the American Academy of Family Practice that 25% of each class graduating from medical school needs to enter family practice residencies to meet the demand for primary care services. The national average for the past eight years has shown a gradually but steady decline of graduating students entering family practice residencies from 12.8% to 10.8% in 1990. In New York State, the record is even more dismal. The average for the past eight years for Downstate Schools is 3.5% and for Upstate schools 9.1% of medical school graduates choosing a career in family practice.

The Clinical Campus of SUNY-Health Science Center was created to address the need for more primary care physicians. The Clinical Campus is a branch campus of the College of Medicine of the SUNY-Health Science Center at Syracuse. The Clinical Campus was established not only to allow for significant and cost-effective expansion in the number of physicians graduating, but also to provide medical education which emphasizes primary care. As a community-based program, the Clinical Campus medical education program is conducted in a variety of health facilities in the Southern Tier of New York State and Northern Tier of Pennsylvania. Hospital affiliates include three general hospitals, a state psychiatric hospital, a state developmental center and a Veteran's Administration Center. The community health agencies, clinics, and private doctors' offices used in the teaching program are spread over a five-county area.

The faculty of the Clinical Campus is regionalized rather than centrally located and numbers over 400 individual physicians and health professionals. About 120 of the faculty are paid on a part-time basis to teach, with the remaining 280 contributing to the academic program voluntarily. The faculty is part of the larger faculty organization of the College of Medicine/SUNY-Health Science Center at Syracuse.

Specifically, the emphasis of the Clinical Campus is a general and primary care orientation featuring ambulatory teaching as well as inpatient instruction. The entire third year curriculum was developed by the Clinical Campus faculty with the guidance of the Clinical Campus Dean and his staff and the approval of SUNY Syracuse Department chairmen. The curriculum includes far more emphasis and experience in ambulatory care settings than traditional models. The hospital clerkships are done at local community hospitals which are affiliated with SUNY-Health Science Center.

Third year Clinical Campus students are required to participate in a longitudinal course called Continuity of Care, which is developed and conducted primarily by family physicians. The Continuity of Care course contains elements of both a clerkship and a preceptorship. All Clinical Campus students participate 1/2 day per week throughout the third year in an assigned primary care physician's office as well as participating in structured primary care teaching activities. In approximately 80% of primary care sites the preceptors are family practice physicians and the remainder are general internists.

From 1981 to 1989, a total of 324 medical students graduated from the Clinical Campus. More than one in five graduates of Binghamton Clinical Campus for the period 1981-1989 chose a residency in family practice (21.1%, n=60). Although there are variations across the study period, the Clinical Campus shows a consistently greater proportion of medical students who choose a residency in family practice.

Approximately one-third of each class is placed in preceptorships which include obstetrical services. Throughout the nine months that data was collected in 1989-1990, these 13 students performed 181 prenatal exams with their preceptors. An expansion of preceptorships which include obstetrics will increase the medical students experience with prenatal care in rural areas.

Of the more than 13,900 patient encounters recorded for the class, 18.2% were pediatric visits. More than half of the preceptorships are located in rural areas with high rates of infant mortality.

Tuition incentives for medical students will increase the acceptance rate for this non-traditional curriculum which emphasizes primary care specialties and produces a significantly greater number of family practitioners than the more traditional medical school curriculum.

Another initiative which SUNY-Health Science Center has undertaken in the last two years is the Rural Medical Education Program (RMED). The Department of Family Medicine places a small number of third year medical students in rural communities full-time for nine months to work and learn with board certified family practice physicians. Students who elect this program live in the rural community and then return to the main campus to complete their fourth year.

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The stated goals of this program include flexibility to meet the needs of students interested in primary care in a non-urban setting, strengthen ties with rural physicians and hospitals in Central New York, help rural communities retain and recruit physicians, and develop a rural network for more effective patient care. The student is able to develop a long term relationship with a preceptor while being immersed in the delivery of primary heath care to a rural area.

To date three students have been placed in Northern and Central New York: Canton-Potsdam, Hamilton-Sherburne-Waterville, and Oswego. An additional eight students will be placed in February/March of 1991. Four areas have expressed an interest in the program: Massena, Lowville, Cortland and Watkins Glen. The program will expand also into communities of Alexandria Bay, Auburn, Dansville, Malone, Rome, Saranac Lake, Trumansburg and Watertown. Many of these areas are in or near federal and/or state designated physician shortage areas.

These communities must provide a financial assistance package to students of approximately $15,000 per site per year as scholarship funds, housing, textbook purchases, computer support and relocation expenses. This support requires no post-training commitment on the part of the student.

Documented patient record from the two students who have completed the program indicate that the students had over 1,000 patient encounters. After the first eight weeks of the program, the students were directly responsible for patient care during more than 90% of their patient contacts. An average of 18% of the patient encounters were pediatric and 12% were obstetrical.

A permanent financial base and tuition support can increase the pool of available placements to accommodate students who might be interested in practicing in rural areas.

The South Central area of upstate New York experiences approximately 7,000 births annually. Approximately 20% of these births are from Chenango and Delaware Counties. Chenango County does not have any prenatal services available within the county. Delaware County, the geographic size of Rhode Island, has a visiting prenatal clinic staffed by nurse midwives. In order to provide more prenatal care in rural areas such as these, the federal government needs to support new initiatives. One example is to make a commitment to nurse midwifery, backed up by financial incentives to schools to develop midwifery programs. Tuition assistance to individuals interested in this extended professional program will help to expand the availability of prenatal care in these rural areas.

To summarize, the causes of infant mortality are many and varied. Lack of insurance, poverty, limited preventive health care, inadequate nutrition and abuse and neglect are contributors to high infant mortality rates. However, even if these problems were magically solved, the problem of high infant mortality rates in South Central New York will not be alleviated, as there are simply not enough providers to care for the rural population. The federal government needs to provide incentives for rural practice in the form of tuition assistance, program development and permanent funding of initiatives which increase rural provision of prenatal and pediatric care.

Respectfully submitted,

Kathylene F. Siska

Kathylene F. Siska, M.S.W.
Research Specialist
SUNY-Health Science Center
Clinical Campus

## PREPARED STATEMENT OF KATHLEEN PERKINS, R.N.C., M.A. HEALTH EDUCATOR, FACULTY, WILSON FAMILY PRACTICE RESIDENCY PROGRAM

### THE EFFECT OF INADEQUATE SOCIAL SUPPORT, HEALTH EDUCATION AND HEALTH CARE ON THE INFANT MORTALITY RATE

Kathleen Perkins, R.N., MA, Certified Community Health Nurse,
Health Educator for Johnson City Family Care Center
Faculty, Wilson Family Medicine Residency Program

Broome County had an Infant Mortality Rate in the range of 7.2 % to 13.8 % from 1986 to 1988. It is a concern for health educators that two census tracts in Johnson City, one which contains the Jonhson City Health Care Center has the highest IMR in Broome County. Accurate statistics for 1989 are not yet available, however Broome County Health Department estimates that percentage has decreased somewhat since then.

Although this is encouraging, we must look at ways our social, economic, and health care system can keep this trend from reversing itself once again. Some of the problems noted that relate to a high IMR are:

Unsafe family environments. Prenatal women and/or infants are often victims of, or besieged by poverty, physical violence, verbal abuse, sexual abuse, inadequate health and dental care, inadequate food and housing, lack of child care, and drug or alcohol abuse.

Language barrier. Many women of foreign extraction are unable to understand physician instructions or health education.

Inconvenient appointments. Often the life-styles of women do not encourage use of appointments available. Some women sleep late and do not show for AM appointments, other women have difficulty in arranging appointments outside of work hours.

**Transportation**. Women who live outside of walking distance have trouble accessing transportation. Medicaid in our county will provide transportation if clients call the day before. Middle and low income women not on medicaid do not have this luxury, and some have no phone to call for a ride, or are unable to avail themselves of this service.

**Environmental contamination**. One wonders about the impact of environmental contamination on the IMR. What is it in this area that is different than other census tracts? Is there more pollution from industrial wastes? Is it the water? Is the inversion effect of fog or smog more in these census tracts? Is it the poor housing? Is it poverty?

**Education**. Is the IMR high because of lack of education in areas that would promote better outcomes for prenatal women and infants?

This short list is undoubtedly simplified and inadequate to describe the wide range of possible reasons for a high IMR in Broome County and the United States as a whole, however it expresses many of community health educators concerns.

Some recommendations that might ensure better outcomes for pregnant women and infants in upstate New York and in the United States are contained in the following paragraphs.

## RECOMMENDATIONS

**A guaranteed income** for all prenatal women and mothers of infants up to one year old to eliminate poverty in these groups. WIC eliminated for this group.

**Mandatory notification of pregnancy** to Public Health Offices for educational, social and counseling support services to secure adequate health care and education. Counseling should include adoption options. All pregnant women should be able to sign adoption papers, irregardless of their age.

**Mandatory free counseling and enforced treatment** for family violence, substance abuse and neglect of self or infant.

**Free health care and immunizations** for all pregnant women and infants. Medicaid certification eliminated for this group.

**Free home based social and health education** to all pregnant women and their families by one consistent Public health nurse. A PHN would be their liaison to other services if needed. The PHN would continue the relationship to the woman and her family over the years. Free professional education and adequate wages would encourage PHN's to remain in the field for long periods of time. PHN's should be assigned to blocks in the city or an indigenous area in the rural areas to be familiar with the subculture of the area and to know all the families in their district. Access to appropriate professional consultation should be assured.

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Federally sponsored translators to provide translators for foreign speaking prenatal women and mothers to ensure adequate health education and treatment.

Free child care. Women need the assurance their income will not be forfeited to the cost of child care. Child care can keep even a middle income family at the poverty level for many years and entices parents to have latch key children. Child care will help promote adequate health care if prenatal women and mothers of infants can seek health care without the burden of taking other children to appointments.

Mandate Health Providers to provide appointments at convenient times for women. This may lessen the use of Emergency Rooms and cut down health care costs arising from their use, will provide continuity of care.

Promote midwifery by educating the public and providing midwifery education and practice monetary incentives to practice in shortage areas. This is a valid alternative. Studies have shown that midwives have better outcomes than physicians (fewer C-Sections and mechanical deliveries).

Use family nurse practitioners to their fullest capacities. Family nurse practitioners are family orientated and are trained to care and promote preventive health care. They are health oriented where doctors are illness oriented. Family nurse practitioners are able to and willing to take the time to teach prenatal women about pregnancy, childbirth and well infant care. They are readily available to the prenatal women and mothers of infants.

Traveling vans to take physicians, midwives or nurse practitioners to rural and high risk areas—to provide on site care. Utilization of a roving van would be more cost effective than maintaining on site clinics in several places.

Federally funded research into environmental or other causes of high IMR.

Informational access to high school students to make them aware of what professionals are needed in maternal and infant health areas. Promotion of and pre-selection of candidates for primary care professions.

Develop education centers in rural or high risk settings for physicians, nurses and social workers. Teach them in the community setting where they are needed. Most higher education goes on in urban centers where high tech is used every day and super specialists do the teaching. Students are indoctrinated in urban specialty training and fear the rural or high risk practices because they have had no practical experience or education in these settings.

Involvement of nursing and medical students in traveling vans to encourage practice in rural and high risk areas. Rewards, stipends or grants to participate would enhance the program.

Financial offsets to primary care physicians, midwives, family nurse practitioners, PHN's and social workers for rural and high risk practices. Family Medicine physicians in particular should be given compensatory incentives to the upmost ability of the government as Family Medicine physicians can care for 97% of all health problems.

Encouraging the use of Family Medicine physicians in itself would cut down on the use of medical specialists and reduce the cost of health care. Family Medicine physicians are trained to work in conjunction with midwives, nurse practitioners, social workers and PHN's to provide continuity of care. This will promote better outcomes for high risk prenatal women and infants. Practitioners need coverage to ensure adequate free time for family, leisure and study to encourage them to remain in undesirable areas. Incentives to practice in rural and high risk areas would help ensure adequate cross coverage of care.

Financial incentives for social workers. Social workers are one of the poorest paid professionals in this country. Health professionals agree that a large percentage of prenatal women and mothers of infants have social issues hindering good outcomes. These issues revolve around poverty, family violence, abuse, dysfunctional families and addictive behavior. Social work intervention is imperative to help resolve some of these issues.

Federal regulation of environmental hazards to protect pregnant women and infants from contaminates.

A widespread federally sponsored advertising campaign to teach prenatal women and mothers of infants important information to prevent infant mortality.

In summary, implementing these recommendations will undoubtedly lower IMR and alter the effect of inadequate social support, health education and health care in upstate New York. They have the potential of being cost effective by cutting bureaucratic red tape in deciding what women and infants are eligible for certain services. The long term costs of poor outcomes in prenatal and infant health care will be lowered and increased productivity of future generations will be promoted.

Respectfully submitted,

Kathleen Perkins

Kathleen Perkins, R.N.C., M.A.
Health Educator
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NORTH COUNTRY CHILDREN'S CLINIC

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July 26, 1990

Honorable George Miller, Chair
Select Committee on Children, Youth and Families
Room H2-385, House Office Building, Annex 2
Washington, D.C. 20515

Dear Congressman Miller:

Thank you for the opportunity to comment regarding maternal and child health issues in upstate New York.

Infant mortality rates can be positively affected with greater emphasis being placed upon prevention. Prevention is not sexy nor does it attract sympathy or attention like a neonatal intensive care unit. Further, the results of prevention are not immediate and therefore, preventive health and education is difficult to sell to funders.

The two most common causes of death in newborns are prematurity and low birth weight. In the greatest percentage of cases both prematurity and low birth weight are preventable. How? Through early, regular, comprehensive prenatal care which includes risk assessment, education, nutrition supplementation (WIC), medical supervision, and case management (social support services). The outcome will generally be a full-term, normal weight newborn. Hundreds of thousands of dollars will be saved by investing thousands of dollars in preventive health, education and support services.

At-risk populations often need financial help and education in order to access comprehensive prenatal and preventive health care. Teenagers, uninsured women, low income women, minority women, and substance abusing women are among the persons that must be targeted through widespread outreach and education efforts. Such efforts should clearly articulate the need for early, comprehensive prenatal care and discuss programs that help pay for such care.

Usually the programs that are most successful in motivating families to comply with sensible, healthy behaviors are those that take the time to help the family to help themselves. Therefore funds should be targeted to community health programs that are "family centered", that advocate for and support families, that empower families through education, financial assistance and case management.

The Women's Infants and Children's Nutrition program (WIC) provides an ideal place to reach at risk families. Funds should be increased for this program as well as for prenatal and primary health care services that operate, collaborate or cooperate with existing WIC services.

Established community health services and providers should be encouraged to work together to improve health outcomes for women and children. Funders should offer incentives to promote such network or consortium development to insure the prudent use of available resources while reducing costly duplication.

We have to stop pouring billions of dollars into the development of services like neonatal intensive care units. We should instead launch a sincere effort to reduce the need for such expensive services by preventing prematurity and low birth weight infants. We must teach families how to stay healthy.

Sincerely,

Janice L. Charles

Janice L. Charles
Executive Director
North Country Children's Clinic, Inc.
35 Empsall Plaza
Watertown, New York 13601

Ms. Charles chairs the North Country Prenatal/Perinatal Council, Inc., a tri-county network devoted to improving health outcomes for all mothers and children in Jefferson, St. Lawrence, and Lewis counties.

She is a member of the New York State Rural Health Council, New York State Department of Health, Albany, New York.

[THE REPORT ENTITLED NORTH COUNTRY CHILDREN'S CLINIC IS RETAINED IN COMMITTEE FILES.]

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July 25, 1990

Dear Congressman Miller,

I am responding to your request for comments regarding how best to improve infant and child health. Our Adolescent Pregnancy Program at North Country Children's Clinic followed over 700 pregnant and parenting teen clients last year in the Northern New York counties of St Lawrence and Jefferson.

Our nurse educators see teens on a daily basis who have little knowledge of childbearing, and less of child rearing. Most of these teens are already high school dropouts when they enter our Program, and have been raised in single parent families. They harbor ill conceived ideas regarding their reproductive potential. Once pregnant, poor nutrition and smoking jeopardize that pregnancy. Once deliverd, these young mothers tell of infant food intakes that are based on whim and their own appetite for Kool Aid.

I assure you that we work diligently through the WIC program, and on an individual basis, to teach reproduction, health, nutrition, safety, and infant development to these teens. But other interventions are needed.

I would urge you to consider an expansion of a full Family Life Curriculum into the early and middle grades, (before these kids drop out), the introduction of school based clinics, and curriculum and day care for pregnant teens enabling them to stay in school. Full funding of the WIC program with its educational component is also essential.

Thank you for this opportunity to express my thoughts.

Sincerely,

Mary Jo Deans

Mary Jo Deans, R.N.
Coordinator, Adolescent Pregnancy Program

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